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Designing ICT based services for intellectually disabled people

Moonen, Rob

2012 Leppävaara, Finland

Laurea University of Applied Sciences
Leppävaara

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Rob Moonen
Degree programme in Service Innovation and Design
Master's thesis
May, 2012

Laurea University of Applied Sciences Abstract
Leppävaara
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Year 2012 Pages 103

The number of intellectually disabled people (ID) is significantly growing in Europe and worldwide. Increasing costs for healthcare and the individual's desire to remain independent in their own homes requires new innovative solutions and services. This thesis analyses how a service design process and methods can be used to design ICT based services that empower intellectually disabled people to have hobbies, communicate, express themselves, and allow for a more independent and safer life. In particular, it develops new information on the use of service design methods for identifying ID people's needs and co-designing ICT based services. The thesis consists out of four different conference papers that have been published and presented on internationally acknowledged conferences and are part of the European ITEA2 projects 'Do-it-Yourself Smart Experiences' and 'Guarantee'.

First, a service design process map was developed to structure the thesis work into different sections. In the first chapter, a detailed literature study was conducted which indicated the importance of ICT technologies for creating opportunities for new service offerings in order to improve the quality of ID people's life. Also it was noticed that only a few publications exist on how to involve ID in the research and design process of new service development.

The second chapter included a qualitative research that was carried out at Rinnekoti-Säätiö, a foundation for disabled people in Finland that produces healthcare and social services to municipalities. The research addressed the use of various service design methods to be able to identify the needs of ID. Besides explaining the suitability of the methods, also the needs and requirements for ICT based services were described. Interviews were considered useful for getting an understanding of the end users basic needs. Video observations, on the other hand, allowed users to show and tell what they are doing in their natural surroundings. The probe methodology, where end users could explain their needs and wishes by taking photos and writing diaries, gave real insights about the latent needs. The focus group allowed participants to influence services that are designed for them in an early phase.

In chapter 3, the service design methods for co-designing ICT based services for ID were addressed. Personas, scenario building, blueprinting, and the business model canvas were selected as co-design methods. First, different personas were created that represent the needs of the intellectually disabled people. Then, based on the personas, different kinds of scenarios were co-designed in a workshop to visualize potential ICT based service concepts. The method of blueprinting was used to identify the roles of various actors within a fall detection and assistance scenario in a smart home setting. A business model canvas was created to identify the business potential of an integrated easy music creation scenario. Finally, demos were developed based on the scenarios (easy music creation, social community) and a blueprint (home safety service).

With the right services it's possible to increase the quality of life and safety of the group of ID. This thesis demonstrated how a service design process and methods can be used to design ICT based services that are meeting requirements on technical, functional, economical, and ethical level. Service design can when implemented correctly, result in optimal user driven service innovations that are business relevant.

Keywords: service design, qualitative research, intellectually disabled people, research methods, ICT, co-creation.

List of conference papers included in the thesis

Study 1

Rob Moonen, Sami Kauppinen, Anusha Iyer, Katri Ojasalo, (2010), “Methods and challenges of doing research with intellectually disabled people: an ongoing empirical study” / UMADR 2010 / 21.06.2010 , 6 p

Study 2

Rob Moonen, Jukka Ojasalo, Heikki Seppälä, Niko Suomalainen (2010), “Designing Services and Systems for Intellectually Disabled People at Home: Preliminary Findings from an Ongoing Empirical Study” / UMADR 2010 / 21.06.2010 , 7 p

Study 3

Jukka Ojasalo, Heikki Seppälä, Rob Moonen, Niko Suomalainen (2010), “Better Technologies and Services for Smart Homes of Disabled People: Empirical Findings from an Explorative Study” / ICSTE / 03.10.2010, 9 p

Study 4

Jukka Ojasalo, Rob Moonen, Heikki Seppälä, Niko Suomalainen (2010), “Designing Services and Systems for Safety of Elderly People at Home; An Ongoing Empirical Study” / SEDE 2010 / 18.06.2010, 7 p

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1 Introduction

1.1 The conference papers presented in the thesis

This thesis consists out of four different conference papers that have been published and presented on internationally acknowledged conferences and are part of European based research and development projects.

Paper 1
The conference paper “Methods and challenges of doing research with intellectually disabled people: an ongoing empirical study” reports on an ongoing empirical study aiming to introduce methods and target challenges of doing user centered research and design with intellectually disabled people.

Paper 2
The conference paper “Designing Services and Systems for Intellectually Disabled People at Home: Preliminary Findings from an Ongoing Empirical Study” discusses an ongoing empirical study aiming at designing safety services for intellectually disabled people who are living at home.

Paper 3
The conference “Better Technologies and Services for Smart Homes of Disabled People: Empirical Findings from an Explorative Study” increases knowledge of technologies and services for disabled people living within a smart-home setting.

Paper 4
The conference paper “Designing Services and Systems for Safety of Elderly People at Home; An Ongoing Empirical Study” explains various technologies and issues that need to be taken into account when designing safety services for elderly at home.

1.2 Background and purpose

One to three percent of the world’s population has an intellectual disability; in Europe an estimated five to fifteen million citizens belong to this group (Pomona II project, 2008). Paper 3 indicates that the number of disabled people is significantly growing in the EU and worldwide in general. An increasing amount of intellectually disabled people is forced or prefers to live independently without external support resulting in more incidents in the home environment. Further, physical and mental constraints are considered to have a drastic impact on the quality and the safety of intellectually disabled (ID) people’s lives. Increasing costs for healthcare and the individual’s desire to remain independent in their own homes

requires new innovative solutions and services.

With the right services it's possible to increase the quality of life and safety of the group of ID people. More specifically, this thesis will address the following research question:

- How can a service design process and methods be used to design ICT based services that empower intellectually disabled to have hobbies, communicate, express themselves, and allow for a more independent and safer life?

More over this thesis will explain in detail the different steps within the service design process while highlighting the main findings. The research and development work and results that are provided within this document are strongly linked to the results of the following two European projects:

- Do-it-Yourself Smart Experiences (DiYSE)
- GUARANTEE, 'A guardian Angel for the Extended Home Environment'

The above mentioned projects are part of ITEA2 which is a strategic pan-European programme for advanced pre-competitive R&D in software or Software-intensive Systems and Services (SiS). ITEA 2 stimulates and coordinates industry-driven, pre-competitive R&D by bringing together partners from industry, universities and research institutes in strategic projects. The programme addresses the following issues:

- The need to understand and master the lag between R&D and commercial innovation;
- Off-shoring is reaching an unprecedented level; and
- The European paradox – great science and technology but poor translation into products
- European R&D intensity is lagging critically behind our main competitors;

(ITEA2, 2012)

1.2.1 Do-it-Yourself Smart Experiences (DiYSE) project

Web based services are considered a common part of people's everyday life. The virtual and physical world is getting increasingly connected by different kinds of smart objects and environments, also called the Internet-of-Things phenomena. The project Do-it-Yourself Smart Experiences allows non technical end-users to easily create, setup, and control their smart home environments and services. The project is carried out by an international consortium which exists out of 40 companies and research partners in Europe. For example Laurea, Philips, Alcatel- Lucent Bell Labs and VTT are some of the partners participating in the project. In Finland, the project focuses on empowering intellectually disabled people to communicate and express themselves with the help of various technologies and ICT solutions and services. The project showcases how latent needs of intellectually disabled people are identified, and service concepts are co-created with the various stakeholders involved. The

goal of the qualitative study that was carried out within the project was to understand the everyday life of the intellectually disabled people, and to find out theirs as well as their support persons' needs and hopes for novel technology.

1.2.2 Guarantee project

Incidents in the home environment among elderly and intellectually disabled persons are a major concern. The Guarantee project researches, designs and develops technologies and services that contribute to a safer home environment. The project develops preventive solutions (such as behavior monitoring) as well as reactive solutions (like fall detection) which offers support and allows intellectually disabled people to live independently at home. The consortium consists out of strong and complementary partners like small companies, research organizations, universities, service providers, and industrial partners.

The user research that is carried out within this project focuses in particular on:

- Social impacts, issues and concerns of ID persons' about safety in their home environment
- Ethical issues including privacy, informed consent and others arising from the deployment and use of home safety products and services
- Designing a conceptual model for safety solution services for ID people at home

1.2.3 Purpose of the thesis

The purpose of the thesis is to find out how a service design process and methods can be used to design ICT based services that empower intellectually disabled to have hobbies, communicate, express themselves, and allow for a more independent and safer life.

In particular, this thesis will develop new information on the use of service design methods. Both the use of service design methods for identifying and understanding the ID' needs and requirements, as well as the use of methods for co-designing ICT based services will be addressed.

1.3 Designing ICT based services

When we want to understand how to design optimal services that include ICT based solutions, it's important to give a closer look at the terminology. The terms 'ICT services' and 'service design' as such will be analyzed within this paragraph in more detail. Understanding the meaning, context in which it can be used, and the relationship between each other, makes it easier to apply in a real setting.

Innovations and development in the field of information and communication technology (ICT) have a profound effect on the way customers experience services. Also it can be noticed that services have migrated from human interaction to substitution of machines for service employees. (Fitzsimmons 2006, 106 - 107) A variety of different kinds of ICT based solutions and services are a normal part of everyday life. Chatting on facebook, reserving your flight on the Internet, getting a confirmation of a flight by sms, and uploading money to your electronic bus card at a kiosk are some practical examples of ICT based services.

The development of new technologies in the past years has stimulated interest in developing new ICT applications for a variety of different kinds of end-users, like people with learning disabilities. ICT can be used to help with communication, learning, and assessment. (Williams 2006, 330-345) Meuter (2000) indicates that ICT technologies can create the opportunity for new service offerings. Mavrou (2011) for example describes that technology can improve the quality of ID people's life by developing tools and services that focus on promoting engagement, inclusion, and facilitate understanding and communication.

ICT can be used for a variety of reasons. Cahill (2003) discusses the term assistive technology (AT) as referred to hardware and software which has been developed to aid people with a disability. Mavrou (2011) mentions that assistive technologies have the ability to allow disabled people to do things that otherwise would have not been possible.

Technology can play a significant role in work with specific disadvantaged groups in the field of communication, education, and learning. The use of ICT based solutions and the Internet have played a major role in developing knowledge and skills of ID. Especially ICT services that aim to compensate for disabilities such as memory problems and daily activities can be seen as beneficial for ID with a mild disability. (Benda 2011, 63 – 69)

Also the field of healthcare benefits from a variety of ICT based solutions, like for example telemedicine which uses IT to provide medical information and services to clients (Baldwin 2002, 309-319). Besides a wide range of application areas and benefits, we need to consider the challenges when developing and utilizing ICT based services. The challenge of a high variety of different software technologies available, and the difficulty of marketing and selling to customers with an increasing amount of requirements need to be taken into consideration. The approach of service design can be used to address the above mentioned challenges and complexities. (Hyötyläinen 2007)

In the past decades the developed economies have moved to a so called service economy (Meroni 2011, 11). In order to understand how to design services we first need to understand the nature of a service. Generally there are three different kinds of characteristics that can

be identified. The first one relates to the fact that services can be considered as processes that consist out of activities. Secondly, services are partly produced and consumed simultaneously. As a third factor we see the consumer as a co-producer of the service production process. Also services are usually perceived in a subjective way; even though the reason for this is because of the intangible nature, many services often include tangible aspects as well. Services can be considered as value based processes (Grönroos 2007, 53 -55) and should therefore add value to its stakeholders. Customers consuming the service should clearly see and experience the added value in order for a service to be successful. The amount of value that is delivered to the customer will eventually make him or her come back for another experience.

The field of service science studies service systems including its co-creational value. Participants, processes, and resources are interacting with each other within a service system setting. Understanding the dynamics of designing services is crucial in order to create value for stakeholders. (Vargo 2008, 145-146)

Service research can be considered as a multidisciplinary field. While new service development focuses on the complete process of developing new services, the service design approach pays special attention to the overall user experience and has its origin in design thinking. Service innovation on the other hand involves the ability to anticipate on the customers' behavior, needs and expectations to develop new service concepts and services. A major challenge which needs to be addressed by service organizations is how to involve customers as early as possible in the development process. (Ojasalo 2009, 216- 222)

Saco (2008) states that "service design a) aims to create services that are useful, usable, desirable, efficient, and effective b) is a human centered approach that focuses on customer experience and the quality of service encounter as the key value for success c) is a holistic approach that considers in an integrated way strategic, system, process, and touch-point design decisions d) is a systematic and iterative process that integrates user-oriented, team-based interdisciplinary approaches and methods in ever-learning cycles."

Service design generally focuses on designing systems and processes that aim to provide a holistic service to the user. It can be considered also as a way for gaining a comprehensive and empathic understanding of customer needs. (Stickdorn 2010, 30 - 32) Service design can involve and transcend within the following disciplines: strategic design, organisational strategy, strategic planning, spatial planning, sociology, project management, production management, network organisation studies, social psychology, behavioural science, innovation management, organisational studies, system design, service operations management, service marketing, interaction design, cognitive psychology, ethnography,

experience design, participatory design, and scenario building. (Meroni 2011, 215) Depending on the setting we can include or discard some of the disciplines.

“Service design helps to innovate (create new) or improve (existing) services to make them more useful, usable, desirable for clients and efficient as well as effective for organizations (Moritz 2005, 7).” It can be noticed that not only the innovation perspective and usability factor play an important role, but also exploitation like business feasibility is considered as an important aspect of service design. Further it can be noticed that technological advances pretty often form the basis for service innovations (Fitzsimmons 2006, 79).

Also expectation management is part of the service design approach. It’s crucial for service providers to know how to match the expectations of customers and provide an optimal service. It’s important to consider the kinds of factors that actually influence the expectations of the customers. When desired expectations refer to the level of service that the customer hopes to receive, adequate expectations include the customer’s acceptance level of performance. (Hsieh 2010, 1128-1144)

In regard to designing systems suitable for intellectually disabled people, the term service system design can be considered as an emerging field. Basically the theory indicates that systems can be designed at different levels. People, technologies, and other resources can be considered as a service system at organizational level. Service design on the other hand includes the components service system, service concept and service process. (Patricio 2011, 2-3)

Peterson states (2008, 87 - 96) that people with disabilities are profoundly affected by what is built around and for them, yet far too often they are not consulted during the various phases of a product's life cycle. To be able to design for these users, it is essential to involve users’ needs, desires and limitations into the design process. The new service or product will eventually be part of the users’ lives and it is needed to know if and how the design will fit their lives and benefit the user. A design approach that involves users throughout the research and design process is inclusive design, an emerging theory, which is influenced by user-centred design. (Dong 2003, 5) Inclusive design would be essential for designing a system that is not just suitable but also likable by various user groups. It would mean giving special considerations to every kind of user, with or without a different ability or cognitive capacity.

Walmsley (2004, 54–64) who follows an even more radical inclusive design tradition, has set out that people with learning difficulties can interview, frame research questions, manage grants, author papers, analyze data, theorize, indeed do all the practical and cognitive tasks associated with research if given the right conditions and support.

1.4 Intellectually disabled people

In order to get a better understanding of intellectually disabled people (ID), a detailed literature study was conducted. Since this thesis focuses on designing services for ID, it's important to get background information that can be used as a starting point. The literature review can be seen as a preparation work before collecting real empirical data which will give deeper insights into the needs and behavior.

Throughout this thesis, the term 'intellectually disabled people' is used, however as indicated in Paper 1, several countries have been using different terms to describe this specific user group. In the UK for example, the term 'people with learning difficulties' is used while in Australia they talk about 'people with intellectual impairments' In the USA 'mental retardation' is continued to be used. (Walmsley 2004, 54 – 64)

The literature review in Paper 2 elaborates on the amount of intellectually disabled people in the world. According to the World Health Organisation, an estimated one to three percent of the world's population has an intellectual disability. From the 490 million citizens of the 27 Member States comprising the European Union, a suggested five million to fifteen million citizens of the European Union are estimated to have an intellectual disability. (Pomona 2008) It is estimated that in Finland there are 35 000 to 40 000 intellectually disabled persons and most of them need individual assistance in living and daily routines. There are 18 institutions in Finland aiming to serve intellectually disabled persons. In January 2009 there were approximately 2000 persons having long-term positions and 4000 person's short-term position in rehabilitation institutions. Approximately 13 000 intellectually disabled persons, from which half are adults, are living with their relatives. Most of the adult intellectually disabled people need an opportunity for self-reliant living. (Finnish government, 2010)

The European Commission is aiming to provide disabled people with the same individual choices and control in their daily lives as non-disabled people. Care and support services are to be more tailored to the specific needs of people with disabilities. The EU also supports the case for the de-institutionalization of disabled people. The European Commission funds studies on the delivery of community-based services needed by disabled people to attain the right levels of security, freedom and independence for community living. (European Commission, 2010)

The life expectancy for persons with intellectual disabilities, along with the general population, has increased during the 20th century. Much of this increase can be attributed to improvements in nutrition, mastering the control of infectious diseases and early intervention in illness management. The most significant increase in life expectancy is reported for

individuals with Down syndrome. In 1900 the life expectancy for persons with Down syndrome was only 9-11 years. In 1946, this was increased to 12 years and more recently to 56. The average age at death for persons with an intellectual disability was reported as 66.1 years. (Haveman, 2010)

Paper 3 indicates that disability can be defined as being limited in daily activities by either physical or mental problems, illness or disability (Eurostat, 2010). There are however plenty of laws and statutes that contain own interpretations of the term disability (Barton 2009, 13-24). There are three main perspectives that we need to consider when trying to understand the nature of disability; medical, economical and socio-political. The medical perspective is based on the functional impairments where a person is viewed as an entity that needs to be cured by experts. (Barton 2009, 22) An economical disability refers to the employment perspective of a person with a disability. The socio-political perspective is at the core of the independent living philosophy where the environment is seen as the disabling factor. (Hahn 1985, Barton 2009, Marinelli 1999)

Further, Paper 3 researches the types of disabling conditions that can arise from a variety of impairments ranging from those acquired at birth to those which arise as part of the ageing process, accidents or illnesses. The different types of disabling conditions usually come under a number of commonly used descriptive headings or terms. They cover mobility, sensory and communication impairments, intellectual impairments and mental health disorders as well as hidden impairments in forms of health problems. Figure 1 shows the distribution of these major types of impairments and health problems within 25 EU countries for the population that is 16 to 64 years old. Figure 2 shows a more detailed picture by splitting these main categories into more specific subcategories.

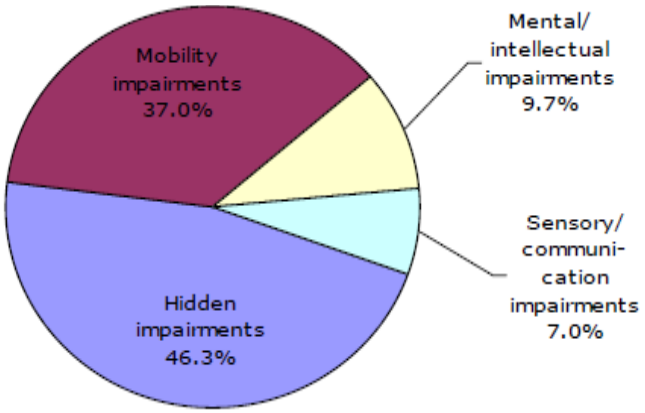


Figure 1: Distribution of major types of disabilities in EU,
(adopted from Buhalis et al., p. 38 based on source Eurostat 2005)

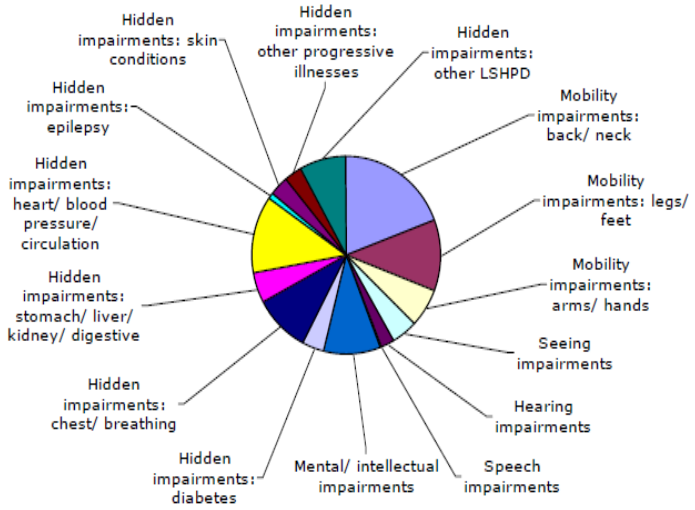


Figure 2: Distribution of subcategories of disabilities in EU,
(adopted from Buhalis et al., 2005. p. 39, based on source Eurostat 2005)

1.5 Structure of the report

When designing a service or system for intellectually disabled people it is important to understand the complete picture. Every design research project must consider how the research participants are embedded in a larger social system and to study the network of key players who inform the user's values, beliefs, actions, lack of actions and stories. (Dishman 2003) The field of service design takes this ecosystem into consideration and offers a holistic approach by designing an integrated service concept that takes the needs of different stakeholders into account. The following service design process (Figure 3) has been developed for the purpose of this thesis and implemented within the previously mentioned European ICT projects ‘DiYSE’ and ‘Guarantee’.

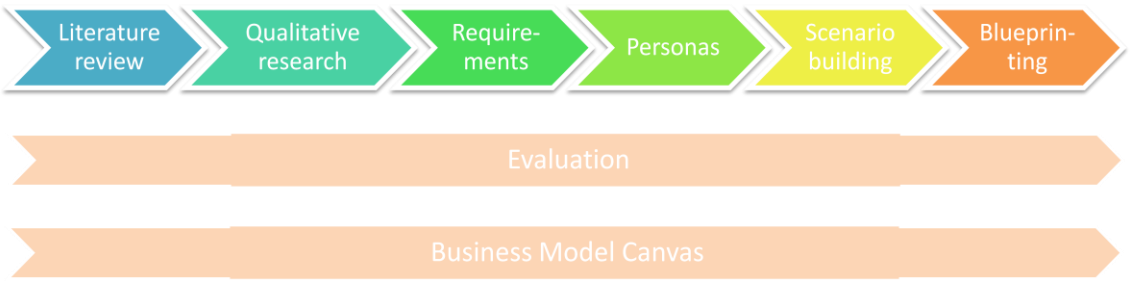


Figure 3: Service Design Process Map

The service design process map was developed in order to structure the thesis and work in a pragmatic manner towards answering the research question. The service design process map is divided into the following steps and chapters: literature review (chapter 1), qualitative research and requirements (chapter 2), personas, scenario building, blueprinting, evaluation, and the business model canvas (chapter 3). Chapter 1 includes a literature review about the terms ‘service design’, ‘ICT services’ and ‘intellectually disabled people’ as such. Chapter 2 ‘qualitative research for understanding user needs’ describes the research process and the use of different kinds of research methods to identify the needs of the end-users. It shares some insights about the challenges and suitability of certain research methods for doing research with intellectually disabled people. Further chapter 2 includes outcomes of the qualitative research in the form of needs and requirements for ICT based services. Hobbies and needs for self expression and social interaction, requirements for interfaces and applications, needs for home safety services, and ethical requirements have been defined. Chapter 3 shows how the service design methods: personas, scenario building, blueprinting, and business model canvas have been utilized to co-design services with various stakeholders. Since the step evaluation has been done throughout the service design process, it can be seen as a continuous loop and will therefore not have a separate chapter; the findings have been integrated throughout the document. Chapter 4 describes the final results of the thesis and answers the main research question. Finally, chapter 5 draws some conclusions. The conference papers and developed personas are included as attachments.

2 Qualitative research for understanding user needs

2.1 Importance of understanding user needs

Involving customers in the service design process tends to have a positive impact on the service performance. Especially having a strong customer focus by including user needs, experiences and requirements in the service design process is crucial in order to be able to design a user centered service that is successful. By understanding latent needs, needs of which customers are unaware, we are able to get deep insights into customer behavior. (Ojasalo K. 2009, 125)

Edvardsson (2006) highlights that understanding and translating the needs of customers correctly is of substantial importance in service development. It's important to not only identify the expressed needs, but especially understand the latent and hidden needs. To be able to get real insights, it's important to understand for example the life style, social context, ethical issues, and certain circumstances of the targeted user group. Also the setting and context in which a service or product is consumed is of substantial importance to be able to develop a service concept which addresses the 'real' needs of customers.

Kaulio (1998, 141-149) presents an analytical framework and an inter-disciplinary review of seven selected approaches dealing with customer, consumer and user involvement in product development. According to Kaulio, different methods support the involvement of customers at different phases of the design process, particularly in: the specification phase, concept development, and prototyping. He also identifies three types of customer involvement namely, design for customers, design with customers and design by customers.

This thesis includes a qualitative research, as part of the service design process, that was carried out with intellectually disabled people and support personnel. In the research, different service design methods were used. The main purpose of this research, within the main context of this thesis, was to find out which service design methods are suitable for identifying ID' needs for ICT based services that would empower them to have hobbies, communicate, express themselves, and allow for a more independent and safer life. Besides the suitability of the service design methods, also the latent needs and requirements for the service itself were identified. In total, the qualitative research consisted out of two different user studies that are reported within the conference papers (1-4).

Paper 1 describes the research process of the user study that was conducted as part of the DiYSE project. The main goal was to understand the everyday life of the intellectually disabled people, and to find out theirs as well as their support persons' needs and hopes for

novel technology. Gaining insights about how to empower intellectually disabled people to have hobbies, communicate and express themselves with the help of various technologies and ICT solutions and services was substantial. Especially identifying the latent needs was of importance.

Papers 2-4 report the user study that was conducted as part of the Guarantee project. The main purpose of the empirical study was to research which social impacts, issues and concerns ID people have about the safety in their home environment. These user findings would potentially contribute in increasing knowledge of designing safety services for ID people.

2.2 Research process and methods

Even though the number of studies which include people with learning disabilities as grant holders, advisors, researchers, authors and disseminators has proliferated, not many publications elaborate on how to conduct research with intellectually disabled people (Walmsley, 2004). There is a need to increase awareness in the specific area of 'research and design with persons with communication impairments' to facilitate further exploration of the experiences of this target group (Carlsson 2007, 1361-1371). Carlsson et al. (2007) reports that qualitative research that has included participants with communication impairments is extremely limited because of methodological challenges involved. In order to succeed it's therefore important to address these challenges. Qualitative research can be seen as ‘a vehicle for purposefully hearing the voices of those who have not been heard before’. It thus has the potential to provide information that can be used to effect change in the lives of disadvantaged groups. (Mmatili, 2009, 14 - 22)

Paper 1 describes the user study that was carried out from December 2009 to February 2010 at Rinnekoti-Säätiö, a foundation for disabled people in Finland, that produces healthcare and social services to municipalities. Altogether 12 different users with a mild or moderate (ICD-10) intellectual disability, varying in age from 21 to 50 years (4 women, 8 men), participated in the study. Figure 4 gives an overview of the timeframe, phases and methods that were included in the user study.

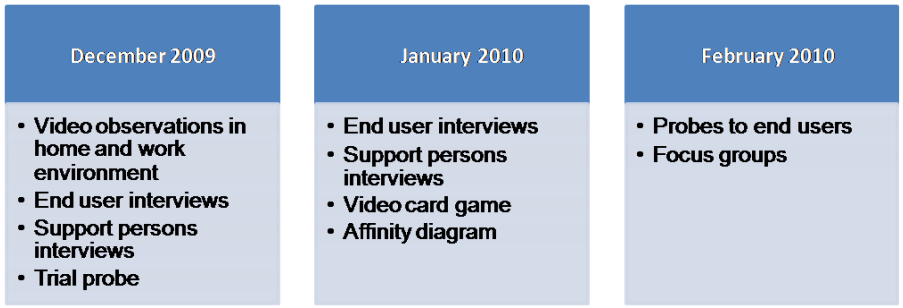


Figure 4: Research process

During the study it was noticed that some of the methods were better suited for research with intellectually disabled people than others. When designing ICT based services, it's important to select the appropriate research methods in order to identify the needs in an optimal way. The following paragraphs describe how the methods have been used and indicate the suitability of the methods for doing research with ID.

2.2.1 Interviews

Interviewing is a relatively cost efficient way for conducting research. One of its main strengths is to access directly what is happening in people's lives. Qualitative interviewing as opposed to a formal questionnaire is likely to get more answers related to a person's view, interpretation of events, understandings, experiences and opinions. (Silverman 2011, 166 – 167)

A total of nine qualitative interview sessions were conducted in which 9 end-users and 17 support people took part. The interview sessions were coordinated by researchers and end user representatives. Before starting the session, a research permission form and a background information form were sent to the users and their support persons for approval. At the beginning of each session the purpose of the interview was first explained. The questions on the interview form included themes of everyday life, activities, and places ID like to visit. Also the role of technology was addressed.

Even though there were some problems with conducting interviews, in most cases this method was found to be useful. The main problem occurred with autistic persons who had difficulties answering the questions because of their disabilities. It could be noticed that this group of people had difficulties finding the right words, and communicating their thoughts and feelings. One participant for example kept repeating the questions which were asked in the interview session. A challenge for the researcher was to use the right words and create appropriate sentences, so the participant would understand the questions. In many cases the

questions must be asked in a simplified manner, because participants have a smaller vocabulary. One of the participants could not answer to any of the questions because he had a severe speech disability. While interviews can be used to gather insights, it's definitely not suitable for every end-user group. Also it shouldn't be used as a stand-alone method.

2.2.2 Video observations

Edvardsson (2006) writes that a useful technique for identifying latent needs is observing customers' use of products and services in normal routines, also called emphatic design. The idea is to observe the customers in the own environment. People give non-verbal cues of their feelings; also it occurs in a natural setting and does not interrupt the usual flow of activity.

We started our research by doing two video observations. The goal was to get a first understanding of the users' activities in the work place and private surroundings. Observation is a useful technique in tracking different contextual data such as work flows, sequences of actions, the physical environment, ergonomic and usability issues as well as interaction between persons and products (Jääskö 2003). Five participants were observed in the sessions from which three were interviewed later on. The observation was recorded with a video recorder; one researcher was filming when the other one was taking notes and asking questions from the participants. When doing user observations, there is a need to combine keen observation and asking well-chosen questions to understand the users' living environment and activity in there (Kelley 2001).

In the first video observation session, four participants were followed one day when they were creating an online newspaper called Marttis at their work environment Nettipaja. At the beginning of the session participants were asked to carry out their normal routines. During the session, predefined questions about the users' work activities were asked. Two supervisors were interviewed during the video observation session in order to gather background information about the daily development work. Another observation session was carried out in one participant's living environment. During this session the participant's free-time activities in the private environment was recorded. The session lasted approximately two hours.

Since the observations were video recorded, it is very important that the users are notified about the filming prior to it and take their consent. Since some of the users have speech limitations and have difficulties to express themselves, it takes time to answer the questions. We noticed that video observation allows the user to show and tell what they are doing in a natural way; connection to the interviewees' everyday life and contexts is important.

Observing can be considered as a good way of looking at how customers behave in their natural surroundings. We noticed the kinds of activities that the intellectually disabled people like to do and got a real in depth understanding of their lives.

2.2.3 Probes

The probe methodology, which is described in detail by Mattelmäki (2006), was selected to get more insights about latent needs, understand human phenomena and explore design opportunities. First a trial probe (self-documenting kit) was given in December 2009 to one participant. We asked the participant to take photographs by phone and write a diary. In February 2010 we sent the probes to five participants after conducting the interviews. Three of the five participants managed to complete the given tasks and sent them back. The goal of the probe kit was to gather specific information about the users' lives in three different areas: social connections, joy / faced problems and technical devices. The probe kit was divided into three 'two-piece' folders that consisted of tasks that the participants were asked to do. On the left side of the folder participants were asked to assemble a collage about the topic. The right side included predefined questions about the collage. Participants were asked to share their thoughts, experiences and ideas by writing, drawing or attaching pictures. One participant was not able to use his hands and hence he was sent a probe in the digital form via email. He used his computer to conduct the given tasks.

The first trial probe that was given to one participant faced some problems, because the user had been prohibited to take photos by mobile phone. We noticed that many of the intellectually disabled people have restrictions with the main purpose to protect their privacy. It's important to take these restrictions, during the planning phase of the user research, into account.

The instructions of the different probe tasks were written through text and symbol language. The text was also simplified so that participants could do the tasks independently. Nevertheless, all the participants who carried out the various tasks needed assistance and guidance. Extra explanation and reading /repeating the sentences were for example needed to help an autistic participant understand the task. Further, the autistic person required intense guidance in order to complete his tasks. One other participant was able to understand the questions; however he needed assistance in answering the questions on his computer. While probes can be considered a challenging research methodology, when applied correctly it can give extremely valuable insights about the latent needs of intellectually disabled people. Also the care givers that participated in the research liked the method. One nurse for example implemented some useful elements of the probe in order to gather feedback related to the services provided by Rinnekoti-Säätiö's foundation.

2.2.4 Focus groups

Focus groups is a method that collects data by involving a small group of people. Within focus groups, also sometimes referred to as a group interview, participants are encouraged to discuss in groups various issues and topics. Typically the session is video recorded and sometimes more sessions on different times and dates are planned to get back to certain topics. (Silverman 2011, 207 – 208)

A focus group session was arranged at the beginning of February 2010 with four participants who also already participated in the previously mentioned interviews. During this session short animations about future scenarios were shown to the participants to evaluate innovative concepts in an early phase. The session started with an introduction of the purpose and was videotaped as well. The animations were watched together several times. Some of the main questions of the focus groups included:

- What is good in the scenario?
- If this kind of service / system would be available, would you willing to use it?
- How can we improve the scenario?

The following findings were noticed when using this particular service design method. First of all the focus group method can get very disruptive with a diverse set of users each with their own clinical needs and attention. It was noticed that the user group of autistic people preferred a familiar group and surrounding within these studies. The ‘focus groups’ method can work well for getting an overall idea about a certain topic by doing group exercises. The method involves the participants in the design process and gives them the opportunity to influence services and products that are designed for them.

2.2.5 General challenges when conducting research with ID

Intellectually disabled people are as diverse as the everyday person, only with varying disabilities, problems and needs. However when planning a user research, it is necessary to take their cognitive and physical capabilities into account in order to perform a task or exercise or even answer questions. Most of them seem keen on answering questions and they enjoy the importance and attention given to them for getting tasks worked on or questions answered. More than with any other user group, it is highly important that they trust you and feel comfortable to interact with you. One way of creating a comfortable atmosphere is by being genuine, honest, friendly and never give the impression you're judgmental.

All in all, interviews were considered useful for getting an understanding of the end users basic needs. This particular method can be sometimes challenging since some end users like autistic persons have difficulties answering questions. The probe methodology, where end users could explain their needs and wishes by taking photos and writing diaries, gave better insights about the latent needs. Video observation on the contrary allowed users to show and tell what they are doing in their natural surroundings. The focus groups method gives participants the opportunity to influence services and products in an early phase of the development process. Combining above mentioned methods resulted in good insights about the kinds of services that would be beneficial for the end-users.

2.2.6 Analyzing research data

Besides choosing the right research methods it's important to also consider beforehand how the research data will eventually be analyzed. Since the research methods observation, interview, and focus group involved video recordings, this paragraph will address how to analyze the video data in an effective way. The research data of the probe method was analyzed by taking notes and reporting the most important findings. Since analyzing this data was rather self explanatory it will not be addressed further.

The films that were recorded tend to be long with many silent moments that are not useful in giving insights. Therefore analyzing videos becomes a long and tedious process, which must then be supplemented with workshops and other methods. We used the video card game (Buur 2000) and affinity diagram to analyze the video data in a relatively fast way.

Jacob Buur and Astrid Soendergaard (2000) discuss that in order to develop user friendly products and services, working with videos should be considered as an integral part of the activities of the design team. It is not a specialized task for experts. Also video should be made available as a resource in the discussions and workshops. The video card game simply intends to help the team cover a bulk of video material in a few hours by segmenting it into smaller chunks in order to identify needs, problems, and prioritize solutions.

The other method, affinity diagram, is a tool that gathers large amounts of language data (ideas, opinions, issues) and organizes them into groupings based on their natural relationships. The Affinity process is often used to group ideas generated by brainstorming. This method taps a team's creativity and intuition. It was created in the 1960s by Japanese anthropologist Jiro Kawakita. (Mindtools) The affinity diagram method is a good way to get people to work on a creative level to address difficult issues. It may be used in situations that are unknown or unexplored by a team, or in circumstances that seem confusing or

disorganized, such as when people with diverse experiences form a new team, or when members have incomplete knowledge of the area of analysis.

The affinity process is formalized in an affinity diagram and is useful when we need to shift through large volumes of data. It is also useful to encourage new patterns of thinking. An affinity exercise is an excellent way to get a group of people to react on a "gut level" rather than mulling things over intellectually. Since brainstorming is the first step in making an affinity Diagram, the team considers all ideas from all members without criticism. This stimulus is often enough to break through traditional or entrenched thinking, enabling the team to develop a creative list of ideas.

During a workshop held on 07.01.2010 a group of Master Degree SID students gathered and participated in the video card game organized at Laurea Leppävaara to identify and structure the intellectually disabled people's needs. The following steps of the video card game were performed.

Before the start of the video card game, video material was edited and cut into different short video clips. When the workshop participants arrived everybody got 10 cards that belonged to a certain video clip. Each card was numbered corresponding to a certain video clip. Then the rules of the game were explained and a short training exercise was conducted to show examples of what can be written upon watching the clips. The members were to watch the video and then analyze or do the interpretation separately in writing on the card. In other words, they had to take notes of what they observed and write this on the cards given to them.

After the previous exercise, the members grouped their observation cards into common themes or sequences according the affinity diagram method. Players were asked to group their cards openly in front of them on the paper sheet on the wall. Each player around the table then briefly described their findings and structure. There were no restrictions on how players needed to group their cards as long as it made sense in terms of design and understanding. Each member was then asked to choose a favorite family of cards. Other players were invited to contribute with cards, which seemed to fit into the same theme. Each card was glued onto a poster with a heading denoting the theme. By selecting favorite themes, the developers took responsibility for explaining the users' needs, problems and wishes. Sometimes a video sequence could give meaning to more than only one theme, so similar cards could belong to different families as well. Finally the players were discussing the different categories with each other, hereby trying to understand the video clips, and initially get different user insights. Since none of the players had seen all clips, they each decided to

show some of their clips to each other to explain why they thought they were relevant. These discussions elaborated on some of the insights.

2.3 Outcomes of the qualitative research: needs and requirements

This chapter described the needs and wishes that have been identified by researching factors that empower intellectually disabled people to have hobbies, communicate, express themselves and allow for a more independent and safer life. More specifically hobbies, needs for self expression and social interaction, requirements for interfaces and applications, needs for home safety solutions, and ethical considerations have been defined.

2.3.1 Hobbies and needs for self expression and social interaction

Based on the user research that was conducted within Paper 1 it could be noticed that the needs that were indicated by the group of intellectually disabled people were strongly related to carrying out a variety of hobbies. The following list includes some of the most important activities that ID like to do.

- Listening to music, singing, karaoke
- Playing music instruments (guitar, piano), figure notes
- Watching music videos
- Dancing
- Theatre, drama club
- Get-togethers, parties, birthdays
- Sports (football, ice hockey, snowboarding)
- Cycling
- Kitchen, cookery
- Writing stories
- Taking care of pet animals, gardening, nature, outdoor activities
- Crafts, painting, drawing
- Children's programs and cartoons on TV

The support personnel highlighted especially the importance of two different categories; self expression and social interaction including the following activities:

- Expressing one's own will, opinions and feelings
- Making new friends safely
- Connection to friends and family
- Develop own skills and learn new skills

The results indicated that both the intellectually disabled participants and their support persons are interested in novel technology. They believe in the possibilities it will give regarding handling day-to-day activities and bringing joy in everyday life.

2.3.2 Requirements for interfaces and applications

Besides getting to know more information about the hobbies and possible application areas, also requirements for applications and interfaces for this special user group have been defined. The requirements are based on interface, usages, and content level.

Interface level
Alternative input and output methods need to be considered since some senses might not be working well and skills are limited. Further it can be noticed that visual interfaces are recommended. For example expressions by visual aids like pictures and symbols helps ID people to focus on the task at hand. Flashing and moving lights should be avoided since some of the individuals have an epilepsy syndrome. Also it is recommended to give the possibility to adjust sound levels and pitches since autistic individuals' abnormality of sensory function and strong reaction to noise may cause challenging behaviour (for example aggression). Further it can be noticed that unexpected pop-ups and information tables work confusingly. Also pull-down menus should be avoided because it complicates searching for certain information.

Usage situation
The users and the support personnel should be provided with clear instructions. Also the location of the service setup should be free of noise and interruption since the end users can be easily distracted. Further it should be possible to set limitations like time limits since by nature they play an important role in the life control and management of intellectually disabled people. Allowing users to act also alone and not only in a group is important because some users have limited interaction skills which makes it challenging to interact within a group setting.

Content
If possible offer degrees of difficulty since the skill level among the end user group can vary substantially. Also encouragement should be offered since the users are sensitive for achievements. ID people should get the feeling that they have reached some goals and are proud of themselves.

2.3.3 Needs for a safe and independent life

The following results are based on the qualitative research from the Guarantee project. The results describe the needs of intellectually disabled people towards safety services and technologies in the home environment. The results are reported in Paper 2 and 3.

Daily routines

The lack of limits can cause different kinds of problems for the people with an intellectual disability. There have been cases where a person doesn't know when to leave from friends in time, and therefore get so fatigued that his mental condition collapses completely. This kind of behavior can apply to various situations where the person doesn't know when to stop pleasure giving activities (using Internet, going out, eating, drinking, cleaning etc). For some of the residents the basic daily routines can be the most troublesome. A nurse said that "One of the participants needs to learn how to brush his teeth every morning, but on the other hand he can manage some other, rather complicated tasks."

Independent living

When interviewing both nurses and residents of Rinnekoti-Säätio, it became obvious that living alone was a common desire among the participants. In every unit, living more independently was a general topic of discussion. Many participants however realized that moving alone in their current condition could be very problematic. Some of the main reasons for a support depending life are the lack of basic skills, and different health conditions like for example diabetes, epilepsy, and mental issues. People with and intellectual disabilities tend to be at risk for social isolation. While technological communication tools are developed as a solution, they sometimes might even increase this risk.

External threat

Many people with a light ID are travelling independently outside. They go to work by bus, see friends or just hang around in the city. Some of the interviewees brought up their occasional fear of being unsafe during for example evenings or nights when they were walking alone. One participant mentioned that "sometimes I feel threatened by groups of young people. I try to avoid confrontation and watch my back".

New situations

Situations or events that are out of line with normal daily routine activities can cause anxiety and a feeling of insecurity. For example in traffic: If the person is used to go to work every day with the same bus and on one day the bus is already gone and he doesn't realize to wait for the next bus, the person might leave and do something totally different. In some cases it is possible that a person gets disoriented and loses track of time and place. This might happen in unfamiliar surroundings where an ID person might feel that the whole world is upside down.

Worry of own condition

Many of the participants were aware of their medical condition and they worried if something bad will happen. One woman had a heart condition and she was already once hospitalized. She feared that it would happen again and that this time she might not get help fast enough which would lead to her death. One man was afraid of epilepsy attacks and pointed out that when they occur he needs assistance immediately. At the point of the study, no efficient emergency systems for the situations described above were present which increased the safety issue.

Go missing

Seeking attention is one of the reasons to go missing for residents in Rinnekoti-Säätiö. A nurse told the following about an interviewee "Sometimes when she is angry, she runs away, but we always find her from the same spot. She is there standing and waiting for us". Also going for a walk during the night time is quite common. For some of the intellectually disabled persons it is hard to understand that some people might get worried if they go missing. Going missing is common among the people who are living in assisted living homes or family homes.

Forgetting things

Both the nurses and the residents realized that leaving the oven on was definitely a common occurring safety hazard. According some nurses, residents were warming the food instead of actually cooking it, making the amount of usage of the oven among the residents rather low. Most of the ID people who were living in semi assisted premises were having their own coffeemakers. Also here, forgetting to turn the machine of was a regular occuring event.

Vulnerability for abuse

According to the nurses, a majority of the ID people were extremely vulnerable for any kind of abuse (sexual, financial, or criminal). It is not uncommon for a mentally disabled person to get in a situation where he does something against his own will, even though he knows the act is wrong.

Traffic

According to the nurses, the behavior in traffic is a significant concern for the mentally disabled persons. Most of the interviewees were able to use public transportation without any problems, if the route is familiar. For people who had lighter disability the traffic didn't

cause problems. Traffic causes problems to persons with more difficult disabilities. Lack of concentration or getting distracted are the main reasons that could lead to dangerous situations.

Situational decision making

Nurses told that when they had a fire drill, only just a few residents know what to do. Some residents just stay in bed and some even hide in the closet. This kind of behavior was especially common in assisted living units where the residents are having more severe disabilities. Situational decision making is hard for the ID persons.

Major conditional issues

The major and the most common conditional issues among the interviewees were:

- Epilepsy
- Diabetes
- Sleep apnea
- Overweight

Because of the conditional issues mentioned above many residents need supervision. It was noticed that especially epilepsy and diabetes are common among the interviewees. Even though sleep apnea was more uncommon, the ones who suffered from it needed supervision during the night time. Accidents that require immediate reaction were epilepsy attacks and collapses due to diabetes.

Privacy

The ones who had the best chances to live independently were also the most aware of their rights in regard to for example privacy. When a person understands his own rights and is able to give consent for the use of monitoring technologies, it's assured that no ethical boundaries are broken. People with ID enjoy the company of other residents but they also appreciate their own privacy. Many of the participants said that they felt most safe in the privacy of their own room.

Privacy vs. security

In many situations the use of monitoring technology is considered to be ethically problematic. We found that it can however also be used to support the privacy of the individuals. There were cases where the residents felt uncomfortable with the check-ins during the night, but

their medical condition (diabetes or epilepsy) required regular visits. These health issues overrule the person's desire for privacy. Monitoring alarm system could enhance the privacy of the individual by reducing or removing the need for control visits. The caregiver would only visit in case of an emergency alerted by the system.

The use of safety technologies

When asked about their opinions related to safety technologies, the attitude was really positive. Many realized that they need help in some situations and were willing to wear or use safety devices. We don't know at this point how the devices are implemented or what they will be like, but in any case, they are likely to receive a good reception. Especially the use of remote assistance was of high interest to both caregivers and participants. The relative of one participant said that "If I could remotely remind or support him in some actions, it would be tremendous."

2.3.4 Ethical considerations

Technological home safety solutions can be considered beneficial for the individual's safety, dignity and independence. However just like any other technology, there is a risk that it could be misused. (Disabled Living Foundation 2009) The end users' rights need to be respected and common understanding should be established regarding the use of the service. In case of ID persons, getting a full consent from the individuals for installing home safety technologies can be problematic as they might not realize what is actually happening. Autonomous decisions of individuals who are capable of making them need to be appreciated, while individuals who have diminished capability to decision-making should be protected. Minimizing the risks related to research, and fair treatment by respecting individuals rights, diversities and differences need to be taken into account. (National Commission 1979, Resnik 2008)

Technologies that support disabled people to live independently at home rather than being institutionalized, can be envisaged as one of the main solutions for a significant reduction of health-care costs when delivering customized support in a non-intrusive and respectful way. A safety service with integrated assistive technologies can, when complied with ethics, support a radical transformation to a safer home environment.

The Guarantee project, which focuses on creating a safer home environment by developing various safety technologies and services, has addressed ethical issues throughout the design and development phases of the various demonstrators. The project investigates if the effort of creating safer homes by means of certain observational technologies is really addressing the safety issues in a sense where it is generating more benefits than harm. Some of the

typical concerns in relation to home monitoring services that have been researched are: privacy, acceptance level, general impact on society, obtaining full consent, autonomy, beneficence, non-maleficence, data security, accuracy, confidentiality, general understanding, usability, quality, intensity of monitoring, and continuity planning.

A questionnaire was developed and answered by demo leaders to gather insights about how they have solved the ethical problems in relation to their surveillance/activity monitoring systems. Some examples of the questions were:

- How is the privacy maintained?
- What personal data is your system gathering?
- How is the data secured?
- What is the acceptance level of the solution?
- How do you make sure that the data collected is accurate enough for reliable decision making?

3 Methods for co-designing services

Coproduction, customer engagement, and involving end-consumers in the design process of services are a constantly evolving process (Voima 2010, 5). Co-creative exercises are used to explore potential directions and gather perspectives of the people involved in the process. The results of these sessions usually include filtered concepts and visualizations of a service that can in a later stage be defined in more detail. Co-creation facilitates different kinds of co-operation initiatives and it encourages a feeling of shared ownership of the new innovations among the creators. (Stickdorn 2010, 197)

Meroni (2011, 43) states that co-design workshops can be used to bring public authorities, end user representatives, and companies together to share their experiences, challenges and ideas. Together the participants can agree on key priorities, opportunities, and areas for improvement.

This chapter introduces several methods that have been used within the projects DiYSE and Guarantee to co-design ICT based services for intellectually disabled people. Methods for co-design can be useful tools to involve different kinds of stakeholders and develop integrated service concepts and solutions. The methods personas creation, scenario building, blueprinting, and business model canvas are described within this chapter.

3.1 Persona development based on identified needs

Personas are fictional profiles that represent an end user group based on their interests and other characteristics. Most of the personas are usually based on research insights from for example interviews and observations. A persona allows for integrating different insights of the target group including but not limited to demographics, and the needs of real users that have been involved in the research. Personas embody real perceptions and feedback of an intended service, prototype, or concept. (Stickdorn 2010, 178) One persona can potentially represent different kinds of needs, characteristics and limitations of several people.

Four different kinds of personas (see Attachment 1) are created based on the needs of the intellectually disabled people that were involved in the research of the DiYSE project that was described in paper 1 and chapter 2 of this thesis. After analyzing the data of the user research by utilizing a video card game and affinity diagram (par 2.2.6), it was clustered into 6 main categories: social life, hobbies, independency, technology/user interface, communication and motor skills. Motor skills and communication describe how limitations affect the users' possibility to communicate and move. Social life describes users' existing social network and contacts while independency indicates the living environment and the

level of independency of using for example public transportation. The hobbies' category describes the user's areas of interest while the technology' category shows which kinds of technology the end-user is currently using.

After clustering the information, the most significant results were selected and used to create the personas. An example of a persona is Figure 5. Lotta is 24 years and she loves to dance, play piano, draw, watch TV, and go for a walk (hobbies). She lives in a one room flat and she is starting to study during next spring (independency). She has six neighbors and they eat together during evenings. During the weekends Lotta spends her time at her parent's home (social life style). She is able to speak well and read short sentences. She has problems to remember things (Communication). Her computer is a big part of her life. She likes to surf the internet, watch pictures and listen to music. Also she has a mobile phone (Technology / interface).

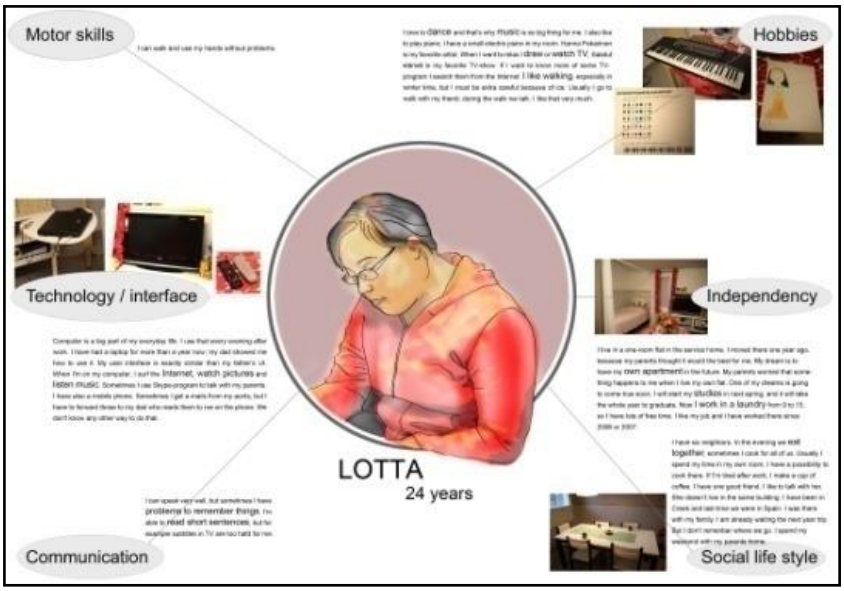


Figure 5: Persona existing out of six categories (Attachment 1).

3.2 Scenario building with stakeholders

Scenarios are based on a relational view that shifts the focus from things to relationships. Imagining a service helps to build up a scenario based on roles, values, and capabilities of the different stakeholders. Also scenarios help in shaping stakeholders' expectations for future solutions and services. Scenario building is considered as a key method for involving different kinds of stakeholders and managing their needs, wishes and expectations. Systematically involving different parties within the process will result in a higher acceptance of the service, since needs have been incorporated from early phase of the service development process. (Meroni 2011, 156)

The four different personas from the previous paragraph were used as a starting point in a scenario building workshop, which was conducted within the DiYSE project. Research organizations, companies, and end-user representatives from Rinnekoti-Säätiö co-designed scenarios and integrated service concepts that could potentially empower intellectually disabled people to do hobbies, communicate, and express themselves.

The workshop started with dividing the above mentioned participants in different groups. Every group would get one persona that was printed on a big poster. Then the group got the assignment to go through the different kinds of needs and characteristics of the particular persona and brainstorm about various service concepts. Basically the participants were challenged to come up with innovative concepts keeping their own organization specific goals on the background. Every group developed an own scenario and visualized this on a big piece of paper. After this one representative of each group presented the ideas to the other groups and partners were able to provide feedback. Eventually six scenarios were ranked and the best ones were chosen for implementation in the project. The following paragraphs display the most significant scenarios that were developed within the workshop.

3.2.1 The social community scenario

The first scenario that was created was called 'social community', see Figure 6. This scenario introduces an Internet based community environment where ID can get in contact with each other and use symbols to communicate.

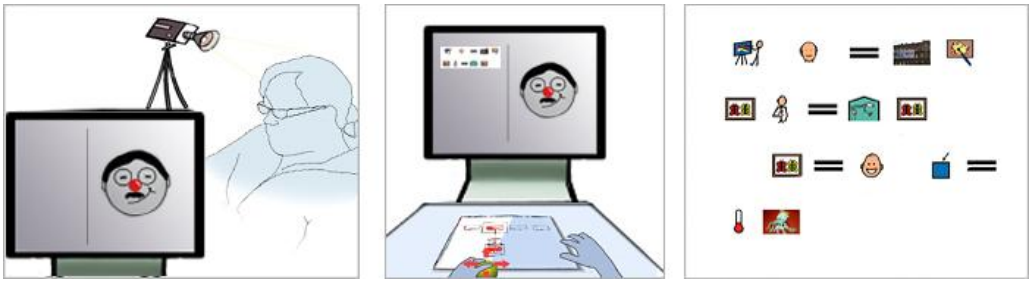


Figure 6: the social community scenario (design by S. Kauppinen)

Lotta wants to create a profile in a social website. Lotta takes a picture of herself and uploads it to the website. After uploading she modifies the

Vesa has already created a profile to the social website. He goes to check if there are any new profiles and he finds

Lotta accepts Vesa's invitation and starts to chat. They use pictograms to chat with each other.

picture by adding glasses and a red nose. Also she makes a personal description by writing with pictograms and recording herself with the camera.	*Lotta. Vesa would like to be in contact with Lotta and sends an invitation to chat with her.*

Eventually the scenario resulted in a final demonstrator that was developed by the University of Tampere. A symbol-based chat application called 'SymbolChat' allows intellectually disabled users and their support personnel to send short symbol-based messages in real time. The application can be easily configured for persons with specific needs and abilities, making it possible to personalize the interaction style with the application.

3.2.2 Simple music creation scenario

The second significant scenario is called the 'simple music creation scenario', see Figure 7. The scenario allows end-users to make music in a simplified manner. For example using different kinds of sensor based music creation applications and instruments would allow a person to create music by just moving the head, or waving with sticks. Also it would be possible to combine a variety of instrument and make music in a group for example.

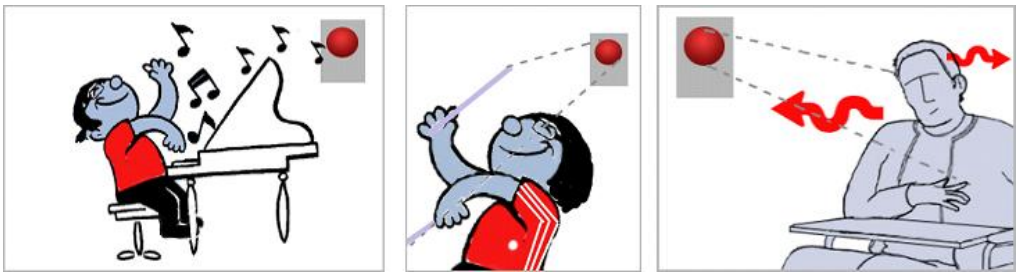


Figure 7: the simple music creation scenario (design by S. Kauppinen)

Lotta plays piano in her home.	*Maija can't play any instrument but she is interested in music. Maija creates music by waving with sticks.* *A computer combines all the sounds and movements and creates music.* *Everybody is able to hear*	*Vesa moves his upper body. The sensor will recognize his movements.*

the created music from the web.

Finally this scenario was implemented as a subset of various demonstrators that allows intellectually disabled people to create music in an easy and intuitive way. Different sensor based music creation applications made it possible for users to make music by moving different body parts. The demonstrators are explained in more detail in the chapter 5.

3.3 Blueprinting the home safety service

Blueprinting is a visual representation of the service process through symbols that represent actors and activities. It is considered to not be as complex as for example some business process modelling tools like UML. The simplicity and graphical display of a blueprint make it easy for all stakeholders to understand and use the model. Also it allows service designers to focus on the service innovation rather than looking at the software and engineering levels. There are five different components that make up the service blueprint: physical evidence, backstage invisible contact / employee actions, onstage visible contact / employee actions, customer actions, and support processes. (Bitner 2008, 71) Blueprinting allows the management to test the service concept on paper before actually implementing the service. It facilitates problem solving and coming up with innovative solutions while highlighting opportunities to improve the quality of the service experience. (Fitzsimmons 2006, 84)

The Guarantee project in Finland aimed to design a service that would improve the safety of intellectually disabled people in a future home setting. A blueprint was developed based on an international home safety service scenario, see Figure 8. First the roles of the different actors including the touch points were identified based on their current technological solutions and services. After this the different solutions were combined in line with the scenario. All of the information was written down and divided into different boxes in order to structure the blueprint. The blueprint helped to identify the roles of the different actors within the service concept and made it possible to communicate ideas in a relatively easy way.

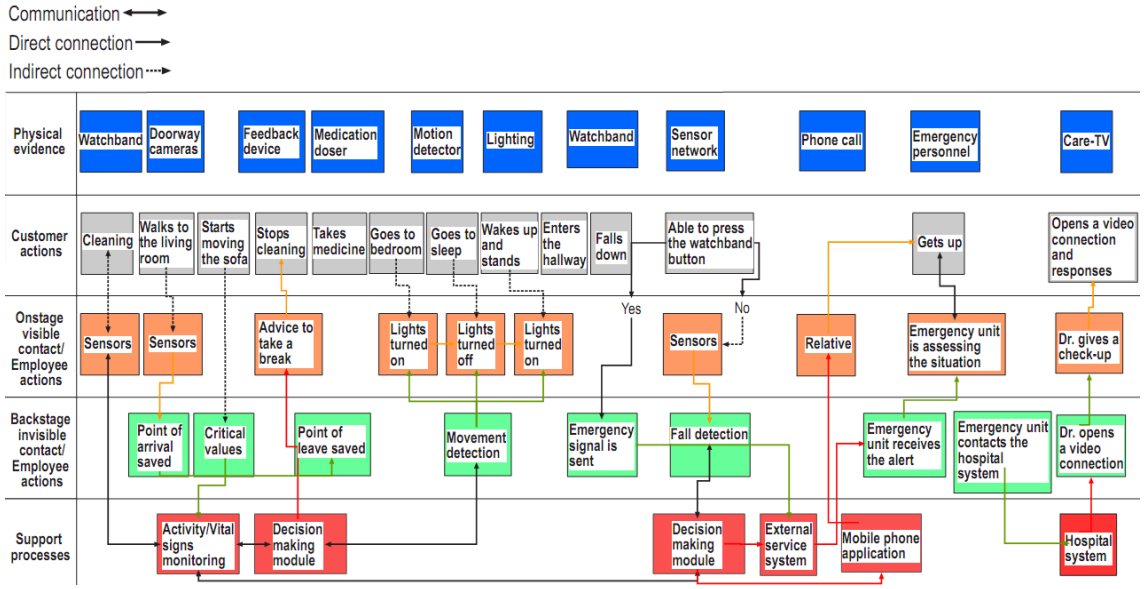


Fig 8: Blueprint of a home safety service concept (design by H. Seppälä)

Since falling can be considered as one of the biggest fatal incidents for both elderly and disabled people, the blueprint is based on a fall detection scenario within a smart home setting. Altogether 12 organizations from which 10 of them were companies and 2 research organization contributed in the blueprint setup. From the 12 organizations, 4 were software firms, 1 develops both software and sensors, 2 were hardware companies, 4 develop both sensors and hardware, and 1 is involved in external services support and human support. All organizations were asked to provide information on the kinds of technologies, systems or services they could potentially offer or develop in the future in relation to smart homes services.

The following is a description of the scenario on which the above shown blueprint is based. Smart Home Resident is cleaning his house. He is wearing a watchband that measures his vital signs. As he moves from one room to another, doorway sensors activate and record the time of arrival and leaving. Smart Home Resident starts to move the sofa and after a while the home sensing system, including the watchband, detects critical health values. The feedback interface advices Smart Home Resident to take a break. Smart Home Resident stops cleaning and sits down for a while. The medication reminder notifies him and Smart Home Resident takes his daily medicine. He walks to the bedroom where the lights turn on automatically. He lies down on the bed and the lights go off. An hour later Smart Home Resident feels a little lightheaded and decides to get a glass of water. As he stands up the lights lid up. Smart Home Resident enters the hallway and just as he is reaching the second stair, he falls down. He forgot the watchband to the bedside table and is now unable to press the alarm button. The surrounding sensing system detects the fall and sends a message to the external service system (ESS). At the same time a message is sent to Smart Home Resident's children who are

able to see a warning on their mobile phones. The ESS works as a mediator to the emergency unit which is dispatched to Smart Home Resident's house. The emergency unit arrives to the scene and helps Smart Home Resident to stand up. They perform a medical examination and discover that nothing is broken in his body. Just to make sure, the emergency unit informs the doctor on call to have a check-up on Smart Home Resident the next day. On the next day the doctor opens a video connection to Smart Home Resident's house. He interviews him and checks all the data available, recorded by the sensors, to be sure that nothing passed through undetected.

3.4 Business Model Canvas

Besides developing solutions that are technically sound and are meeting the requirements of the end users, it's important to give a look at the exploitation perspective and market potential of the intended products, services and solutions. Eventually a company's main goal is to bring their innovations to the market and make business out of it.

The business model concept can be used to structure and visualize the company's interaction with suppliers, partners, and customers. Even though there are several explanations of business model concept, all sources relate to the fact that customer value creation is considered as one of the core elements. Secondly the earning logic of a business should be included, since it explains the profitability of a business. Third the value network of the business need to be considered since it relates to the ecosystems of the business. Next business models should also include the resources and capabilities the firm has and it should discuss the strategic decisions, choices and principles. (Nenonen 2009)

A business model can be seen as a conceptual tool that contains a set of elements and their relationships and allows expressing a company‘s logic of earning money. (Osterwalder, 2010) The business model canvas, which was developed by Osterwalder and Pigneur is a strategic management tool, a visual template preformatted within nine blocks of the business model (Customer Segments, Value Proposition, Channels, Customer Relationships, Revenue Streams, Key Resources, Key Activities, Key Partnerships, and Cost Structure).

When delivering a service or developing a product we first need to wonder what the added value is to our customers and how we are addressing the needs (value proposition). In order to identify our business value network we need to identify our main partners (key partners). Also it's important to keep track of the kinds of activities that are necessary to provide the service (key activities). Further we need to know which resources there are necessary, for example physical, intellectual, human, financial, software (key resources). Then we need to gain knowledge about the way the customers are consuming the service, for example independently or community based (customer relationship). We need to decide which sales

and marketing channels like a website, own store, partner store etc are best suitable to reach the intended customer segment (channels). In order to target right, we need to know beforehand to which customers, including its characteristics, we are planning to sell to (customer segment). Last but definitely not least, we need to indentify if the business is feasible from a financial perspective. It's hereby important to indentify the main costs that are inherent to the business (cost structure) and we need to know what the main income streams will be like for example licensing, subscription fees, or component based selling (revenue stream).

The business model canvas (BMC) has been utilized as a tool to indicate the business potential for some of the most important and relevant use cases and solutions. During a workshop by Laurea, VTT, Music Makers, and Delicode, a common integrated business model was developed for the easy music creation scenario. First participants needed to present answers to questions that were sent to them a week before the meeting. The questions were based on the building blocks of the BMC. During the presentations, one person was writing short notes and posted them on top of the BMC that was displayed on a big A1 sheet of paper. Finally the BMC included contributions (sticky notes) of all participants. After this, the contributions were combined into a common integrated business model canvas which represented a music service to children. Even though the BMC did not provide a final answer, it was a good first attempt to come up with a common business approach that integrated the needs of all stakeholders.

4 Results: using service design in developing services for ID

This chapter includes the results of the thesis which answers the main research question:

- How can a service design process and methods be used to design ICT based services that empower intellectually disabled to have hobbies, communicate, express themselves, and allow for a more independent and safer life?

The results are validated within two international projects and four different conference papers. In particular, this thesis focused on the development of new information on the use of service design methods for both understanding the users' needs as well as co-designing ICT based services.

First, a service design process map was developed in order to structure the thesis and work in a pragmatic manner towards answering the research question. The service design process map includes the following sections: literature review (chapter 1), qualitative research and requirements (chapter 2), personas, scenario building, blueprinting, evaluation, and the business model canvas (chapter 3).

The first section of the thesis focused on conducting a literature study about the terms 'service design', 'ICT services' and 'intellectually disabled people' as such. The study indicated that roughly five to fifteen million citizens of Europe are estimated to have an intellectually disability. The European Commission is aiming to provide disabled people with the same individual choices and control in their daily lives as non-disabled people. De-institutionalizing and independent living are hereby highly encouraged.

It was noticed that ICT technologies can create the opportunity for new service offerings that can improve the quality of ID people's life by focusing on promoting engagement, inclusion, and facilitating understanding and communication. Also there was mentioned that the use of ICT based solutions has played a major role in developing knowledge and skills of ID (Benda 2011, 63 – 69). When we want to be able to design services for intellectually disabled people it is essential to involve their needs, desires and limitations into the design process. Peterson (2008, 87 - 96) describes that people with disabilities are profoundly affected by what is built around and for them, but yet far too often they are not consulted during the various phases of a product's life cycle. Carlsson (2007) and Walmsley (2004) indicate that there are not many publications that elaborate on how to conduct research with intellectually disabled people.

The second chapter of this thesis addressed the above mentioned challenges and explained how to use service design methods in order to understand the needs of intellectually disabled people. Besides explaining the suitability of the methods, also the needs and requirements for ICT based services were identified. A user research was carried out at Rinnekoti-Säätiö, a foundation for disabled people in Finland that produces healthcare and social services to municipalities. The study group included 12 different users with a mild or moderate (ICD-10) intellectual disability, varying in age from 21 to 50 years.

Interviews, video observations, probes, and focus groups were selected as service design methods for understanding the needs of intellectually disabled people. Some of the main findings included the following. First, when planning a user research, it is necessary to take ID people's cognitive and physical capabilities into account in order to perform a task, exercise or even answer questions. More than with any other user group, it is highly important that they trust you and feel comfortable to interact with you. One way of creating a comfortable atmosphere is by being genuine, honest, friendly, and never give the impression you're judgmental.

Interviews were considered useful for getting an understanding of the end users basic needs. This particular method can be sometimes challenging since some end users like autistic persons have difficulties answering questions. Video observations allowed users to show and tell what they were doing in their natural surroundings. It's a useful method for understanding the kinds of activities that the intellectually disabled people like to do in their lives. It allows tracking different contextual data such as work flows, sequences of actions, the physical environment, ergonomic and usability issues as well as interaction between persons and products (Jääskö 2003).

The probe methodology, where end users could explain their needs and wishes by taking photos and writing diaries, gave real insights about the latent needs. Ojasalo, K. (2009) and Edvardsson (2006) highlight the importance of identifying and understanding the latent needs of customers in order to get insights about for example the life style, social context, ethical issues and certain behaviors. Also it could be noticed that it's important to take restrictions into account that protect the privacy of intellectually disabled people; for example some end-users were prohibited to take photos with their mobile phones. While probes can be considered as a challenging service design method, when applied correctly it can give extremely valuable insights about the end-users latent needs.

Another service design method, the focus group, involved the participants in the design process and gave them the opportunity to influence services that were designed for them. It

however can sometimes get disruptive with a diverse set of users each with their own clinical needs and attention.

Utilizing the above mentioned methods resulted in lots of user research data. A video card game and affinity diagram was considered useful for analyzing the data in a relatively fast way. Some of the main user research findings included the following. Listening to music, dancing, theatre, cooking, but also the need for expressing an own will, and making new friends were highly appreciated by ID. Assistance in traffic, protection against abuse, and preventing immoderation of pleasure giving activities, are some of the needs for safety technologies that were identified. Also ethical issues like privacy, acceptance level, and data security were taken into consideration.

In chapter 3, the service design methods for co-designing ICT based services for intellectually disabled people were addressed. Personas, scenario building, blueprinting, and the business model canvas were used as service design methods.

Personas embody real perceptions and feedback of an intended service, prototype, or concept (Stickdorn 2010, 178). Four different personas were created that represent stakeholders of the service. The main purpose of the created personas was to see the needs, wishes and limitations belonging to the following main categories: social life, hobbies, independency, technology/user interface, communication and motor skills. Based on the personas, different kinds of scenarios were created. Scenario building is considered as a key method for involving different kinds of stakeholders and managing their needs, wishes and expectations. Systematically involving different parties within the process will result in a higher acceptance of the service, since needs have been incorporated from early phase of the service development process. (Meroni 2011, 156) Two scenarios, simple music creation and social community, were presented as significant cases that were co-created by research organizations, companies, and end-user representatives.

A blueprint was developed based on the fall detection and assistance scenario within a smart home setting. Blueprinting allows the management to test the service concept on paper before actually implementing the service. It facilitates problem solving and coming up with innovative solutions while highlighting opportunities to improve the quality of the service experience. (Fitzsimmons 2006, 84) The developed blueprint was based on roles of 12 companies and research organizations within Europe. It was considered as a useful tool for communicating the different expectations and contributions of the partners. Besides developing solutions that are technically sound and are meeting the requirements of the end users, it’s important to give a look at the exploitation perspective and market potential of

the intended products, services and solutions. The business model canvas was introduced and helpful for defining the business potential within nine different building blocks.

5 Conclusions

This thesis introduced a service design process and methods for designing ICT based services that empower intellectually disabled to have hobbies, communicate, express themselves, and allow for a more independent and safer life. It developed new information on how to use service design methods for identifying ID people's needs and co-designing ICT based services.

First, a service design process map was developed to structure the thesis work accordingly and divide it into different sections; literature review (section 1), qualitative research and requirements (section 2), personas, scenario building, blueprinting, evaluation, and the business model canvas (section 3).

The literature study reviewed in detail the terms 'service design', 'ICT services' and 'intellectually disabled people'. Noticed was that far too often intellectually disabled people are not consulted in the design process. Also not many publications can be found on how to conduct research with intellectually disabled people.

Section 2, qualitative research for understanding user needs, explained how to use service design methods in order to identify the needs of intellectually disabled people in an optimal way. It also included an actual identification of the needs and requirements for ICT based services based on a qualitative research in co-operation with Rinnekoti-Säätiö, a foundation for disabled people in Finland that produces healthcare and social services to municipalities.

Interviews, video observations, probes, and focus groups were selected as service design methods for understanding the needs of intellectually disabled people. Interviews were considered useful for getting an understanding of the end users basic needs. Video observations, on the other hand, allowed users to show and tell what they are doing in their natural surroundings. It's a useful method for understanding the kinds of activities that the intellectually disabled people like to do in their lives. The probe methodology, where end users could explain their needs and wishes by taking photos and writing diaries, gave real insights about the latent needs. The focus group allowed participants to influence services that are designed for them. Combining the four above mentioned service design methods resulted in a good understanding of the needs of ID for ICT based services.

In section 3, the service design methods for co-designing ICT based services for intellectually disabled people were addressed. Personas, scenario building, blueprinting, and the business model canvas were all used as co-design methods. First different personas were created to represent the needs of the stakeholders in the service concept. Then, based on the personas, different kinds of scenarios were created that represented ICT based service concepts. The

method of blueprinting was used to identify the roles of various actors of a fall detection and assistance scenario within a smart home setting.

Then, the business model canvas was used to identify the business potential of an integrated easy music creation scenario. Finally, demos were developed based on the scenarios (easy music creation and social community) and a blueprint (home safety service). The demos give a good indication about how the user' needs are incorporated in the service development.

Figure 9 shows the demo that has been developed by VTT originally for the end user group of intellectually disabled people. The main idea is that end-users learn to play guitar in an easy, educative and intuitive way by pushing different colored buttons. This guitar hero adaptation is an innovative way to educate intellectually disabled people as well as children and let them create music in a simplified matter.

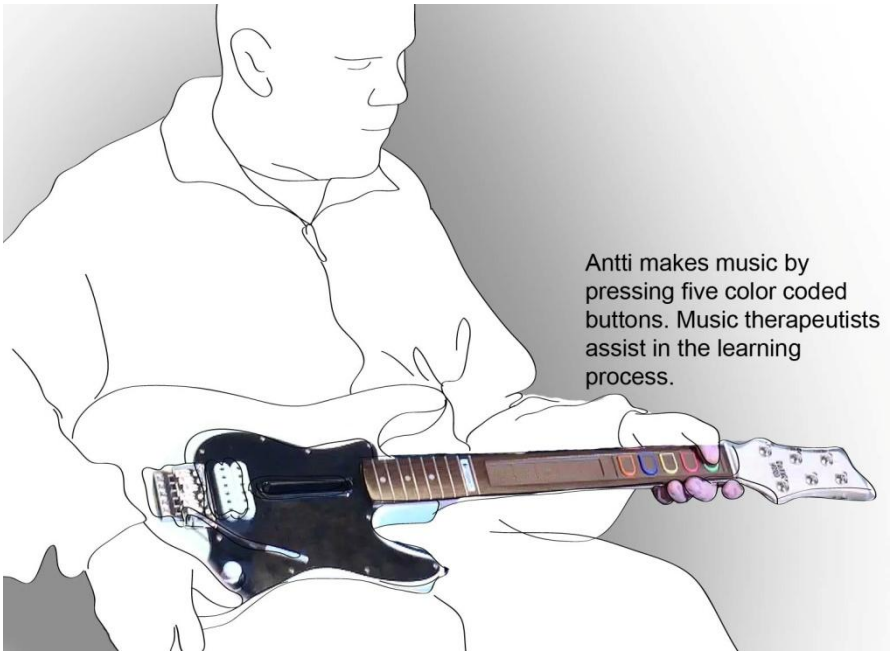


Fig 9: easy music creation guitar demo (design by S. Kauppinen)

Figure 10 gives an example of intellectually disabled people that are able to make music by moving different parts of their body in front of a Kinect device. An end user can for example by just moving their hands, play a virtual drum set that is displayed on a TV or wall. Delicode developed the natural interaction software (NI mate, www.ni-mate.com) for the Kinect which allows end users to interact in an intuitive way.

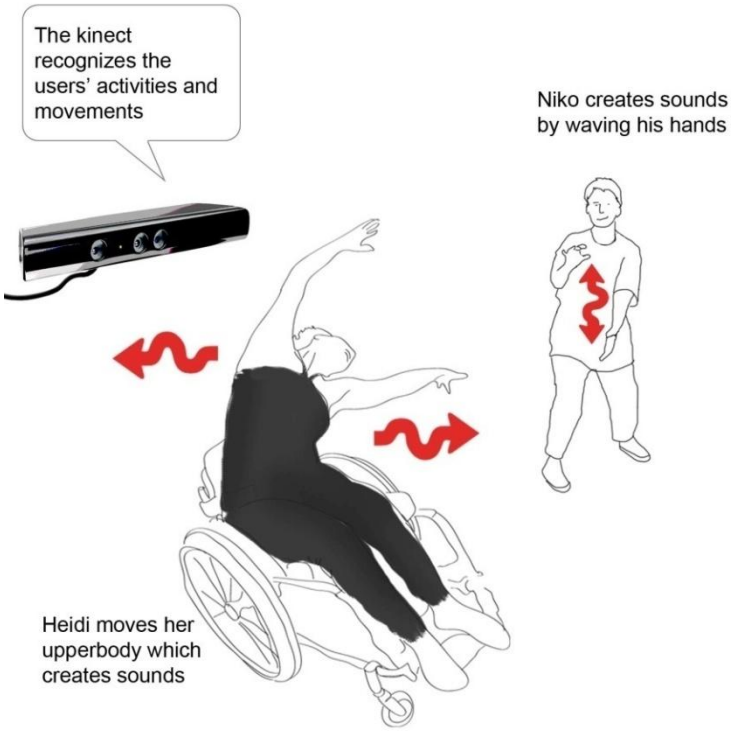


Fig 10: natural interaction software (design by S. Kauppinen)

The easy music creation demos (Figure 9 and 10) were very well accepted by the end-users. During different workshops, evaluation sessions and even a concert, the ID people showed a lot of excitement, joy and skills when making music in groups or individually.

Figure 11 introduces the SymbolChat application that has been developed by the University of Tampere. This particular application allows intellectually disabled users and their support personnel to send short symbol-based messages in real time. The application can be easily configured for persons with specific needs and abilities, making it possible to personalize the interaction style with the application. The application was co-created and evaluated with various stakeholders.

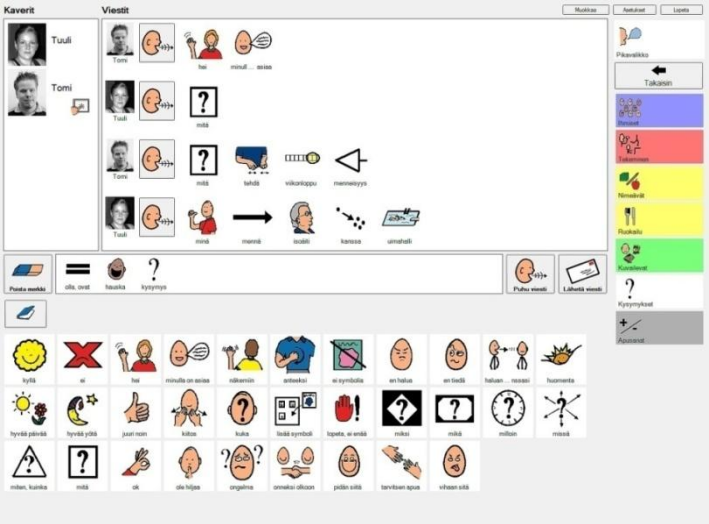


Figure 11: symbol chat application
(adopted from Keskinen et al., 2012)

Figure 12 shows a demonstrator that is developed by VTT within the Guarantee project and is partly based on the blueprint from par 3.3 and the international use case called 'characterization of elderly normal behavior'. It includes a vacuum robot as a platform for developing safety services that addresses incident related emergency situations. This particular solution could potentially enhance the feeling of safety in the everyday life of intellectually disabled and elderly people. The vacuum robot is able to locate a person that falls, initiate communication with the person, and provide alerts to care givers if necessary.

Figure 12: Fall assistance robotic vacuum cleaner
(adopted from Kantorovitch et al., 2012)

With the right services it's possible to increase the quality of life and safety of the group of ID people. This thesis demonstrated how a service design process and methods have been utilized to develop ICT based services that are meeting requirements on technical, functional,

economical, and ethical level. Service design can when implemented correctly, result in optimal user driven service innovations that are business relevant. It can be considered as an effective way for connecting the fields of user research, technology, and business development.

The service design process and methods that are introduced in this thesis can be used and implemented in future service design work. Depending on the situation, certain methods and part of the process will be more relevant. It should be clearly noticed that even though this thesis has attempted to develop new information on how to use service design methods, it should not be seen as a final guideline. Since only few publications are available, more research is needed about the suitability of service design methods and services for the end user group of intellectually disabled people.

References

Baldwin, L., Clarke, M., Eldabi, T., Jones, R., 2002. Telemedicine and its role in improving communication in healthcare. 309 – 319.

Barton, B., 2009. Dreams Deferred: Disability Definitions, Data, Models, and Perspectives, Journal of Sociology & Social Welfare, Volume XXXVI, No. 4, Dec. 2009, pp. 13-24.

Benda, P., Havlicek, Z., lohr, Z., Havranek, M. 2011. ICT helps to overcome disabilities. Agris on-line Papers in Economics and Informatics. Volume 3, number 4.

Bitner, Ostrom, Morgan, 2008. Service Blueprinting: a practical technique for service innovation. California management review.

Buhalis, D., Eichhorn, V., Michopoulou, E., Miller, G., 2005. Accessibility Market and Stakeholder Analysis, One-Stop-Shop for Accessible Tourism in Europe, OSSATE, University of Surrey,
http://www.ossate.org/doc_resources/OSSATE_Market&Stakeholder%20Analysis_Public_Version_Fina.pdf viewed 20 May 2010

Buur J., Soendergaard A. 2000.Video Card Game: An augmented environment for User Centred Design discussions, ACM press. 11-18.

Cahill, K., Cornish, S. 2003. Assistive technology for users in the Royal Borough of Kensington and Chelsea public libraries in the UK. Vol 37. Issue 3. 190 - 193

Carlsson, E., Paterson, B., Scott-Findlay, S., Ehnfors, M., Ehrenberg, A. 2007.Qualitative Health Research: Methodological Issues in Interviews Involving People Whit Communication Impairments After Acquired Brain Damage, Sage publications. 1361-1371.

Disabled Living Foundation, Ethical issues with assistive technology, 2009.
http://www.livingmadeeasy.org.uk/scenario.php?csid=43, viewed 9.4.2010.

Dishman, E., 2003. Designing for the New Old.

Dong H., Keates S., Clarkson P.J., Cassim J. 2003. Implementing Inclusive Design: The Discrepancy between Theory and Practice.

Edvardsson, B., Gustafsson, A., Kristensson, P., Magnusson, P., Matthing, J. 2006. Involving customers in new service development. Vol 11.

European Commission, People with disabilities, http://ec.europa.eu/social/main.jsp?catId=429, viewed 4.1.2010.

Eurostat, Health Statistics, Key Data on Health, 2002. http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-08-02-002/EN/KS-08-02-002-EN.PDF, viewed 20 May 2010.
Eurostat, 2005. Population and Social Conditions: Percentual Distribution of Types of Disability by Sex and Age Group.

Finnish Government, Government Resolution on the program for arranging housing and connecting services for the mentally disabled, 2010, http://www.valtioneuvosto.fi/toiminta/periaatepaatokset/periaatepaatos/fi.jsp?oid=286028, viewed 21 Jan 2010.

Fitzsimmons, 2006. Service Management, Operations strategy Information Technology, Fifth edition, McGraw Hill.

Grönroos, C., 2007. Service management and marketing. Customer Management in Service Competition. Third Edition.

Hahn, H., 1985. Changing perception of disability and the future of rehabilitation, in Social influences in rehabilitation planning: Blueprint for the 21st century, A report of the Ninth Mary E. Switzer Memorial Seminar, Alexandria, VA: National Rehabilitation Association, L. Perlman & G. Austin, Eds., pp. 53-64.

Haveman, Heller, Lee, Maaskant, Shooshtari, Strydom. 2019. Report on the State of Science on Health Risks and Ageing in People with Intellectual Disabilities, http://www.iassid.org/pdf/State%20of%20Science%20on%20Health%20Risks.pdf, Dortmund, 2009, viewed 8.1.2010.

Hsieh, Y., Yuan, S. 2010. Modeling service experience design processes with customer expectation management: A system dynamics perspective. Kybernetes, vol 37, 1128 – 1144.

Hyötyläinen, M., Möller, K. 2007. Service packaging: key to successful provisioning of ICT business solutions. Journal of Service Marketing. Vol. 21. 304 – 312.

Iyer, A., de Roeck, D. 2010. Empowering people to connect & create with smart technology. Sixth Swiss Design Network Conference.

ITEA2. 2012.www.itea2.org, viewed on 27.03.2012.

Jääskö, V., Mattelmäki, T., 2003. Observing and Probing. DPPI proceedings on designing pleasurable products and interfaces.

Kantorivitch, J., Laikari, A., Pehkonen, V., Seppälä, H.,Väre, J. 2012. Fall assistance for elderly people, utilizing a household robot. IEEE Robotics and Automation Magazine. Submitted.

Kaulio, M., 1998. Customer, consumer and user involvement in product development: A framework and a review of selected methods. Total Quality Management, 9, 141-149.

Kauppinen, S., Kotimäki, T., Heimonen, T., Turunen, M., Laivo, T. 2011. Chataamista ilman kirjoitustaitoa. Ketju Magazine. 1-2011.

Kelley T., The Art of Innovation, 2001.

Keskinen, T., Heimonen, T., Turunen, M., Rajaniemi, J., Kauppinen, S. 2012. SymbolChat: Picture-based Communication Platform for Users with Intellectual Disabilities.

Marinelli, R., Dell Orto, A. 1999. The psychological and social impact of disability, 4th edition, New York, Springer Publishing Company, 1999.

Mattelmäki, T. 2006. Design probes.

Mavrou, K., 2011. Assistive technology as an emerging policy and practice: Processes, challenges and future directions. Technology and Disability, 23. 41-52.

Meroni, A., 2011, Design for Services. Design for social responsibilities series. Gower.

Meuter, M. Ostrom, A., Roundtree, R. Bitner, M. 2000. Selfservice Technologies: Understanding customer satisfaction with technology based service encounters. vol. 64. July.

Mindtools. http://www.mindtools.com/pages/article/newTMC_86.htm. Last time viewed on 02.05.2012.

Mmatli, T, 2009. Translating disability-related research into evidence-based advocacy: the role of people with disabilities.

Moonen, R., Kauppinen, K., Iyer, A., Ojasalo, K. 2010. Methods and challenges of doing research with intellectually disabled people: an ongoing empirical study. Kona. UMADR. Paper 1.

Moonen, R., Ojasalo, J., Seppälä, H., Suomalainen, N. 2010, Designing Services and Systems for Intellectually Disabled People at Home: Preliminary Findings from an Ongoing Empirical Study. UMADR 2010. Paper 2.

Moritz, S., 2005. Service Design, practical access to an involving field, London.

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research, http://www.uwrf.edu/grants/IRB/BelmontReport.pdf, viewed 09.04.2010.

Nenonen, Storbacka, 2009. Business model design: conceptualizing networked value co-creation, the 2009 forum on services, Naples.

Ojasalo, J., Seppälä, H., Moonen, R., Suomalainen, N. 2010. Better Technologies and Services for Smart Homes of Disabled People: Empirical Findings from an Explorative Study. ICSTE. Paper 3.

Ojasalo, J., Moonen, R., Seppälä, H., Suomalainen, N. 2010. Designing Services and Systems for Safety of Elderly People at Home; An Ongoing Empirical Study. San Fransisco. SEDE 2010. Paper 4.

Ojasalo, K., 2009. Business and Design competences in Service Innovation and Development, The business review, Cambridge, Vol 13, Nr1.

Ojasalo, K., 2009. Designing Industrial Services – What is the role of the customer? , The business Review, Cambridge, Vol 14, Nr 1, Dec 2009.

Osterwalder, A., Pigneur, Y. 2010. Business model generation: a handbook for visionaries, game changers, and challengers.

Patricio, Fisk, Falca, Cunha, Constantine, 2011. Multilevel Service Design: from customer value constellation to service experience blueprinting, Journal of Service Research.

Peterson, W., 2008. Top Stroke Rehabil. Role of Persons with a Disability in the Design Process, Thomas Land Publishers, Inc. 87–96.

Pomona II project, Health indicators for people with intellectual disabilities, 2008.

Sherrard, .J, Tonge, B. , Ozanne-Smith, J., 2001. Injury in young people with intellectual disability: descriptive epidemiology, 2001, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1730696/pdf/v007p00056.pdf, viewed 3.1.2010.

Resnik, D., Zeldin, D., 2008. Environmental health research on hazards in the home and the duty to warn, Published in final edited form as: Bioethics, 2008.

Rinnekoti-Säätiö, 2009. Foundation's Incident Report.

Saco, R., Goncalves, A. 2008. Service design: an appraisal. Design Management Review, 19. 10.

Silverman, D. 2011. Interpreting qualitative data. 4th edition. Sage publications.

Stickdorn, Sneider. 2010. This is service design thinking. Basics-Tools-Cases.

Voima, Heinonen, Strandvik, 2010. Exploring Customer Value Formation: A Customer Dominant Logic Perspective. Hanken School of Economics Working Papers.

Vargo, Maglio, Akaka. 2008. On value and value co-creation : a service systems and service logic perspective. European management journal, 26.

Walmsley J., 2004. Nursing Inquiry 2004: Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research, Blackwell Publishing Ltd. 54–64.

Williams, P., Jamali, H., Nicholas, D. 2006. Using ICT with people with special educational needs: what the literature tells us. 330 – 345.

Attachments

Attachment 1 Personas

Design by S. Kauppinen.

Motor skills

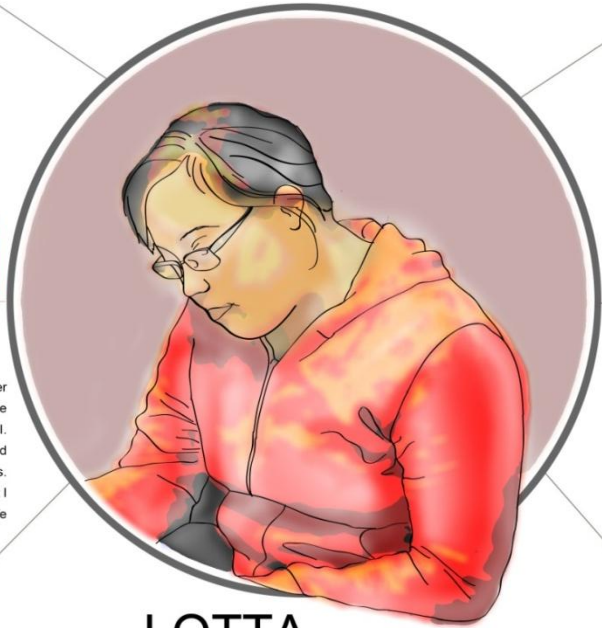
I can walk and use my hands without problems.

Hobbies

I love to **dance** and that's why **music** is so big thing for me. I also like to play piano; I have a small electric piano in my room. Hanna Pakarinen is my favorite artist. When I want to relax I **draw** or **watch TV**, Salatut elämät is my favorite TV-show. If I want to know more of some TV-program I search them from the Internet. **I like walking**, especially in winter time, but I must be extra careful because of ice. Usually I go to walk with my friend; during the walk we talk. I like that very much.

Technology / interface

Computer is a big part of my everyday life. I use that every evening after work. I have had a laptop for more than a year now; my dad showed me how to use it. My user interface is exactly similar than my father's UI. When I'm on my computer, I surf the **Internet**, **watch pictures** and **listen music**. Sometimes I use Skype-program to talk with my parents. I have also a mobile phone. Sometimes I get e-mails from my aunts, but I have to forward those to my dad who reads them to me on the phone. We don't know any other way to do that.



LOTTA

24 years

Independency

I live in a one-room flat in the service home. I moved there one year ago, because my parents thought it would the best for me. My dream is to have my **own apartment** in the future. My parents worried that some-thing happens to me when I live my own flat. One of my dreams is going to come true soon, I will start my **studies** in next spring, and it will take the whole year to graduate. Now **I work in a laundry** from 9 to 15, so I have lots of free time. I like my job and i have worked there since 2006 or 2007.

Communication

I can speak very well, but sometimes I have **problems to remember things**. I'm able to **read short sentences**, but for example subtitles in TV are too hafd for me.

Social life style

I have six neighbors. In the evening we **eat together**, sometimes I cook for all of us. Usually I spend my time in my own room, I have a possibility to cook there. If I'm tired after work, I make a cup of coffee. I have one good friend. I like to talk with her. She doesn't live in the same building. I have been in Creek and last time we were in Spain. I was there with my family. I am already waiting the next year trip. But I don't remember where we go. I spend my weekend with my parents home.

Motor skills

I have no problems with moving. I think you could say that I have good motor skills.

Hobbies

I have lots of hobbies, on Wednesdays I have gymnastic music, we dance there. I am also in a theatre group. Every Sunday I go to church where we sing hymns. In the evenings I watch TV, mostly children programs, Finnish movies and concerts. Sometimes I miss programs because I don't know what time it is.

Technology / interface

I have a mobile phone and I know how to answer to that, but I can't make calls. I have never used a computer, but I think I could try. I have heard about the Internet, but I have never tried that either. Actually I don't know anybody who use the Internet. I have never tested speech recognition.

Independency

My job is to take care of running things, for example I check that people safely arrives to work. It's mostly Independent work. I like to live in Rinnekoti area; it's really nice to walk around that place. I don't want to go to any public places alone; I need nurse to come with me. It feels safer if nurse is with me. Time management is difficult for me. I can't understand watch, because of that I usually have to wait hours to get my medicines. I have had a mobile phone for many years now, but nurses have to dial numbers if I want to call somebody.

MAIJA

I don't remember my age, it must be around 45 to 50 years.

I live in one-room apartment in assisted living house. I have lived there for eight years now, I think. I know everybody from my house, nurses and inhabitants too. I pick up food for my friend Tanja. I like to meet new people, but lately I haven't met new people at all. My friend Pirjo lives in Lapinjärvi, I visit her few times in a year. It would be nice to contact her more often.

Communication

I can speak clearly and people understands what I want to say. I have never learned how to read or write. Sometimes I receive SMS's, nurses have to read those to me. My visual memory is good, if I see a nice picture I can remember it for long time.

Social life style

Motor skills

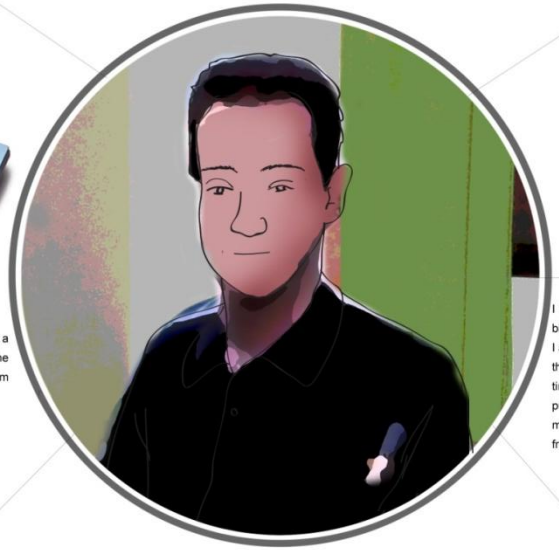
I have no problems with moving.

Hobbies

I like to make 3 dimensional objects of cardboard. I like to copy details. I got a guitar for a Christmas present and I did the same kind of guitar of cardboard. I play the guitar that I made. I like to also draw. I like cycling and football. Sometimes I walk or work in garden if someone asks me to do that. I like to watch TV; children programs are the best.

Technology / interface

I have a radio in my room; I like listening Finnish music. I have a Playstation in my grandparents place. I play games with that. In the school I use a computer. Usually I watch movies about games from internet. I also make some school exercise with computer.



MIKKO

21 years

Independency

I live in a family home. I have a room in the big house. There live five smaller children but I am an adult. Around the house is a field. In the morning I go to school. I am always at time. I like to be in school – I can use a computer there. My mom from family home takes me to school. In the evening she picks me up from the school.

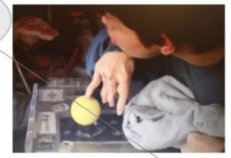
Communication

I have difficulties to form sentences. I repeat other people questions. That's why people have difficulties to understand me. For me it is easier to write. I can write most of words correctly. Sometimes I have to ask nurses help.

Social life style

I have one friend in my working place. I don't want to meet or contact him in the evening time. I have another friend who lives in other place. I don't see him so often. Sometimes I go to visit my grandparents place. Everything has to go in same way when I go there. First I watch the same movie that I watch every time. Then I can start to do other things.

Motor skills



I have to use an electric wheelchair to go from place to another; I use a joystick for steering. I have difficulties to control my muscles. For example I have difficulties to use my hands; I am not able to eat by myself; nurses have to help me. But when I watch TV I can use a remote control with my fingers, if it is in front of me on a desk.

Hobbies

I love movies! I watch movies at home and once in a week I go to cinema with my personal nurse. Music is also a huge thing for me. I like wheelchair dancing; I move my upper body when I'm dancing. I also go to swim once a week. Sometimes I play a football game with my computer. One of the nurses has to put CD into my computer so that I can play that game.

Technology / interface

I use computer every day at work and home. The program called Grid helps me to write emails and documents, it converts symbols to text. I understand those symbols very well. It is very difficult to add new symbols to Grid. I also have an application which reads text for me from the computer. In my room there is buttons on top of my bed, from there I can operate different kind of things in my room, for example turn on the TV.

I work in a web workshop; it's in Rinnekoti area. I go to work with a taxi because I live in a one-room apartment in a supported home in Vantaa. It's difficult for me to use public transportation. In the supported home are nurses that help me to eat and wash, but also my dad helps me when nobody else can do it. Sometimes I'm worried about fire.

Independency

VESA

28 years

I have difficulties to talk. For me it takes a lot of time to say something. People don't understand me because it's hard for me to make understandable words. That's why people afraid to start a conversation with me. Sometimes in the church someone wants to speak with me. After a conversation I feel tired. I understand both Finnish and English.

Communication

I'm a social person and I like to meet new people. I have three friends who live in the same building as I, also my dad lives in there. My dream is to find a nice girl and get married. Sometimes I feel lonely.

Social life style

Attachment 2 Paper 1: Conference paper at UMADR / UMAP 2010

Title: ‘Methods and Challenges for Doing Research with Intellectually Disabled People: an Ongoing Empirical Study’

Abstract. This paper reports on an ongoing empirical study aiming to introduce methods and target challenges of doing user centered research and design with intellectually disabled people. First this paper will explain why research is needed within this area. Then it introduces several research and design methodologies. After this it explains the ongoing empirical study. Then it will describe the usability, drawbacks and challenges of implementing certain methods with intellectually disabled people. Finally it will give some recommendations of doing research and design with challenging target groups. This paper results from ITEA2 (Information Technology for European Advancement) strategic cluster project “DIYSE – Do-it-Yourself Smart Experiences”.

1 Introduction

Even though the number of studies which include people with learning disabilities as grant holders, advisors, researchers, authors and disseminators has proliferated [1], not many publications elaborate on how to conduct research with intellectually disabled people. There is a need to increase awareness in the specific area of 'research and design with persons with communication impairments' to facilitate further exploration of the experiences of this target group. [2]

The research presented in this paper is part of the European ITEA2 project 'Do-it-Yourself Smart Experiences' (DIYSE) aiming at designing highly personalized meaningful communication / interaction experience for intellectually disabled people. The purpose of this paper is to explore and evaluate methods for doing user studies with intellectually disabled people. Carlsson et al (2007) reports that qualitative research that has included participants with communication impairments is extremely limited because of methodological challenges involved. [2] In order to succeed it's therefore important to address certain challenges. Throughout this paper, the name 'intellectually disabled people' is used, however several countries have been using different names to describe this specific user group. In the UK for example, the term 'people with learning difficulties’ is used while in Australia they talk about ‘people with intellectual impairments’ In the USA ‘mental retardation’ is continued to be used. [3]

2 Design methods

Peterson states that people with disabilities are profoundly affected by what is built around and for them, yet far too often they are not consulted during the various phases of a product's life cycle.[4] To be able to design for these users, it is essential to involve users' needs, desires and limitations into the design process. The new service or product will eventually be part of the users' lives and it is needed to know if and how the design will fit their lives and benefit the user. A design approach that involves users throughout the research and design process is inclusive design, an emerging theory, which is influenced by user-centred design. [5] Inclusive design would be essential for designing a system that is not just suitable but also likable by various user groups. It would mean giving special considerations to every kind of user, with or without a different ability or cognitive capacity.'

Walmsley who follows an even more radical inclusive design tradition, has set out that people with learning difficulties can interview, frame research questions, manage grants, author papers, analyze data, theorize, indeed do all the practical and cognitive tasks associated with research if given the right conditions and support. [2]

When designing a service or system for intellectually disabled people it is important to understand the complete picture. Every design research project must consider how the research participants are embedded in a larger social system and to study the network of key players who inform the user's values, beliefs, actions, lack of actions and stories. [6] The method of service design takes this ecosystem into consideration and offers a holistic approach by designing an integrated service concept that takes the needs of different stakeholders into account.

3 Ongoing empirical study

Pugach refers to qualitative research as 'a vehicle for purposefully hearing the voices of those who have not been heard before'. It thus has the potential to provide information that can be used to effect change in the lives of disadvantaged groups. [7] This paper is part of an ongoing qualitative user study which researches the latent needs of intellectually disabled people. The following methods have been used; interviews, video observations, probes, and focus groups.

The user study was carried out from December 2009 to February 2010 at Rinnekoti-Säätiö, a foundation for disabled people in Finland, that produces healthcare and social services to municipalities. Altogether 10 different users with a mild or moderate (ICD-10) intellectual disability, varying in age from 21 to 50 years (4 women, 8 men), participated in the study. A total of nine interview sessions were conducted in which 9 end-users and 17 support people took part. Two video observations were done and 6 probes were sent out to be completed.

We started our research by doing two video observations. The goal was to get a first understanding of the users' activities in the work place and private surroundings. Observation is a useful technique in tracking different contextual data such as work flows, sequences of actions, the physical environment, ergonomic and usability issues as well as interaction between persons and products.[8] Five participants were observed in the sessions from which three were interviewed later on. The observation was recorded with a video recorder; one researcher was filming when the other one was taking notes and asking questions from the participants. When doing user observations, there is a need to combine keen observation and asking well-chosen questions to understand the users' living environment and activity in there. [9]

In the first video observation session, four participants were followed one day when they were creating an online newspaper called Marttis. At the beginning of the session participants were asked to carry out their normal routines. During the session predefined questions about the users' work activities were asked. Two supervisors were interviewed during the video observation session in order to gather background information about the daily development work. Another observation session was carried out in one participant's living environment. During this session the participant's free-time activities in the private environment was recorded. The session lasted approximately two hours.

We selected the probe methodology to get more insights about latent needs, understand human phenomena and explore design opportunities. First a trial probe (self-documenting kit) was given in December 2009 to one participant. We asked the participant to take photographs by phone and write a diary. In February 2010 we sent the probes to five participants after conducting the interviews. Three of the five participants managed to complete the given tasks and sent them back. The goal of the probe kit was to gather specific information about the users' lives in three different areas: social connections, joy / faced problems and technical devices. The probe kit was divided into three 'two-piece' folders that consisted of tasks that the participants were asked to do. On the left side of the folder participants were asked to assemble a collage about the topic. The right side included predefined questions about the collage. Participants were asked to share their thoughts, experiences and ideas by writing, drawing or attaching pictures. One participant was not able to use his hands and hence he was sent a probe in the digital form via email. He used his computer to conduct the given tasks.

Also a focus group session was arranged at the beginning of February 2010. During this session short animations about future scenarios were shown to four participants to evaluate innovative concepts in an early phase.

4 Findings

During the study it was noticed that some of the methods were better suited for research with intellectually disabled people than others. We also encountered several challenges.

4.1 Interview

Even though there were some problems with conducting structured interviews, in most cases this method was found to be useful. The main problem occurred with autistic persons who had difficulties answering the questions because of their disabilities. It could be noticed that this group of people had difficulties finding the right words, and communicating their thoughts and feelings. One participant for example kept repeating the questions which were asked in the interview session. A challenge for the researcher was to use the right words and create appropriate sentences, so the participant would understand the questions. In many cases the questions must be asked in a simplified manner, because participants have a smaller vocabulary. One of the participants could not answer to any of the questions because he had a severe speech disability. While interviews can be used to gather insights, it's definitely not suitable for every end-user group. Also it shouldn't be used as a stand-alone method.

4.2 Probe

The first trial probe that was given to one participant faced some problems, because the user had been prohibited to take photos by mobile phone. We noticed that many of the intellectually disabled people have restrictions with the main purpose to protect their privacy. It's important to take these restrictions, during the planning phase of the user research, into account.

The instructions of the different probe tasks were written through text and symbol language. The text was also simplified so that participants could do the tasks independently. Nevertheless, all the participants who carried out the various tasks needed assistance and guidance. Extra explanation and reading /repeating the sentences were for example needed to help an autistic participant understand the task. Further, the autistic person required intense guidance in order to complete his tasks. One other participant was able to understand the questions; however he needed assistance in answering the questions on his computer. While probes can be considered a challenging research methodology, when applied correctly it can give extremely valuable insights about the latent needs of intellectually disabled people. Also the care givers that participated in the research liked the method. One nurse for

example implemented some useful elements of the probe in order to gather feedback related to the services provided by Rinnekoti-Säätiö's foundation.

4.3 Video observation

It is very important that the users are notified about the filming prior to it and take their consent. Since some of the users have speech limitations and have difficulties to express themselves, it takes time to answer the questions. We noticed that video observation allows the user to show and tell what they are doing in a natural way; connection to the interviewees' everyday life and contexts is important. The films tend to be long with many silent moments that are not useful in giving insights. Therefore analyzing videos becomes a long and tedious process, which must then be supplemented with workshops and other methods. We used for example a video card game [10], which helped us to analyze the data in a very effective way.

4.4 Focus group

This method can get very disruptive with a diverse set of users each with their own clinical needs and attention. It was noticed that the user group of autistic people preferred a familiar group and surrounding within these studies.

The 'focus group' method can work well for getting an overall idea about a certain topic by doing group exercises. The method involves the participants in the design process and gives them the opportunity to influence services and products that are designed for them.

4.5 General challenges

Intellectually disabled people are as diverse as the everyday person, only with varying disabilities, problems and needs. However when planning a user research, it is necessary to take their cognitive and physical capabilities into account in order to perform a task or exercise or even answer questions.
Most of them seem keen on answering questions and they enjoy the importance and attention given to them for getting tasks worked on or questions answered. More than with any other user group, it is highly important that they trust you and feel comfortable to interact with you. One way of creating a comfortable atmosphere is by being genuine, honest, friendly and never give the impression you're judgmental.

5 Conclusion

This paper introduced methods and addressed challenges for doing research with intellectually disabled people. First it reviewed design research methods that could be most suited for intellectually disabled users. Then it described the ongoing empirical study in which a set of methods were chosen and modified to ensure they befitted the nature of the project, and its stakeholders. After that, findings regarding the use of interviews, video observations, probes, and focus groups have been reported. These findings indicate which kinds of challenges need to be addressed when preparing and using certain methods for doing research with this challenging user group.

References

1. Walmsley J.: Nursing Inquiry 2004: Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research, Blackwell Publishing Ltd. 54–64, 2004.
2. Carlsson E., Paterson B. L., S. Scott-Findlay, M. Ehnfors, A. Ehrenberg: Qualitative Health Research: Methodological Issues in Interviews Involving People Whit Communication Impairments After Acquired Brain Damage, Sage publications. 1361-1371, 2007.
3.Walmsley J.: Nursing Inquiry 2004: Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research, Blackwell Publishing Ltd. 54–64, 2004.
4. Peterson W.: Top Stroke Rehabil 2008: Role of Persons with a Disability in the Design Process, Thomas Land Publishers, Inc. 87–96, 2008.
5. Dong H., Keates S., Clarkson P.J., Cassim J. Implementing Inclusive Design: The Discrepancy between Theory and Practice, 2003.
6. Dishman E., Designing for the New Old, 2003.
7. Mmatli T. O.: Translating disability-related research into evidence-based advocacy: the role of people with disabilities, 2009.
8. Jääskö V., Mattelmäki T., Observing and Probing.
9. Kelley T., The Art of Innovation, 2001.
10. Buur J., Soendergaard A.: Video Card Game: An augmented environment for User Centred Design discussions, ACM press. 11-18, 2000.

Attachment 3 Paper 2: Conference paper at UMADR / UMAP 2010

Title: 'Designing Services and Systems for Intellectually Disabled People at Home: Preliminary Findings from an Ongoing Empirical Study.

Abstract. This article reports on an ongoing empirical study aiming at designing safety services for intellectually disabled people living at home. Firstly, this article discusses why research and development in this area is needed. Then, it briefly discusses ethical issues when implementing safety technologies in the home environment. Next, it explains the ongoing empirical study. After that, it explains the method. Then, it introduces preliminary empirical findings related to safety concerns of people with cognitive disabilities living at home. The preliminary empirical findings of the present user research relate to the following three aspects: firstly, disabled persons' desire to live at home vs. motivation to take care of basic routines independently; secondly, using wristband technologies; and thirdly, disabled persons' desire for increased social interaction. Finally, the conclusions are drawn. This paper results from ITEA2 (Information Technology for European Advancement) strategic cluster project "GUARANTEE – A Guardian Angel for the Extended Home Environment".

1 Introduction

According to the World Health Organisation, an estimated one to three percent of the world's population has an intellectual disability. From the 490 million citizens of the 27 Member States comprising the European Union, a suggested five million to fifteen million citizens of the European Union are estimated to have an intellectual disability. [1] It is estimated that in Finland, where this study is conducted, there are 35 000 to 40 000 intellectually disabled persons from which most of these people need individual assistance in living and daily routines. There are 18 institutions in Finland aiming to serve intellectually disabled persons. In January 2009 there were approximately 2000 persons having long-term positions and 4000 person's short-term position in rehabilitation institutions. Approximately 13 000 intellectually disabled persons, from which half are adults, are living with their relatives. Most of the adult intellectually disabled people need an opportunity for self-reliant living. [2]

The European Commission is aiming to provide disabled people with the same individual choices and control in their daily lives as non-disabled people. Care and support services are to be more tailored to the specific needs of people with disabilities. The EU also supports the case for the de-institutionalization of disabled people. The European Commission funds studies on the delivery of community-based services needed by disabled people to attain the right levels of security, freedom and independence for community living. [3]

The life expectancy for persons with intellectual disabilities, along with the general population, has increased during the 20th century. Much of this increase can be attributed to improvements in nutrition, mastering the control of infectious diseases and early intervention in illness management. The most significant increase in life expectancy is reported for individuals with Down syndrome. In 1900 the life expectancy for persons with Down syndrome was only 9-11 years. In 1946, this was increased to 12 years and more recently to 56. The average age at death for persons with an intellectual disability was reported as 66.1 years. [4]

Increased injury risk in this population is likely because of limitations in both understanding hazards and coping with environmental challenges. [5] When creating a safe home environment for intellectually disabled it's crucial to have a deep understanding of the different safety hazards and concerns affecting the quality of life. However, there is a lack of documentation and data available of the kind of safety related incidents, and concerns for the population of intellectual disability. General population injury epidemiology and prevention strategies are well documented, but there is no clear picture quantifying the potential public health impact of injury and relevant prevention for populations with Intellectual Disability (ID). [5]

However, some sporadically data on this issue can be found. For example, Rinnekoti-Säätiö, which is a foundation for ID people in Finland, reported on the following incidents during 2008. Altogether, 160 incidents were reported, from which 78 incidents occurred through falling and slipping indoors/ outdoors, 28 incidents happened through falling from certain objects. 29 self-inflicted incidents occurred based on arguments, communication disruption, impatience, and self-destructiveness. Also there were 94 violent situations and 135 potentially violent situations reported. From the violent situations it was related; 28 times to hitting and /or kicking, 46 times to biting, and 10 times to scratching. Another 9 cases were reported where patients were missing. Five of the patients were brought back by the personnel of the Rinnekoti-Säätiö, two of the patients came back by themselves and two times a missing patient was tracked down by Rinnekoti's own search group. [6]

Even though above mentioned facts give an indication of different safety issues for the ID group, there is an urgent need for a deeper understanding and increasing knowledge in the area. This report will investigate safety concerns and issues related to intellectually disabled people living at home. The purpose of this empirical study is to increase the knowledge of designing safety services for ID people. This report results from an on-going action research. Thus, any results and conclusions suggested here are tentative.

2 Ethical issues of home safety technologies

Technological home safety solutions can be considered beneficial for the individual's safety, dignity and independence. However just like any other technology, there is a risk that it could be misused. [7] The end users' rights need to be respected and common understanding should be established regarding the use of the service. In case of ID persons, getting a full consent from the individuals for installing home safety technologies can be problematic as they might not realize what is actually happening.

Autonomous decisions of individuals who are capable of making them need to be appreciated, while individuals who have diminished capability to decision-making should be protected. Minimizing the risks related to research, and fair treatment by respecting individuals rights, diversities and differences need to be taken into account. [8,9]

Technologies that support disabled people to live independently at home rather than being institutionalized, can be envisaged as one of the main solutions for a significant reduction of health-care costs when delivering customized support in a non-intrusive and respectful way. A safety service with integrated assistive technologies can, when complied with ethics, support a radical transformation to a safer home environment.

3 An ongoing empirical study: the purpose

Next, the present ongoing empirical study is presented, a research project which is part of ITEA2 (Information Technology for European Advancement) strategic cluster project "GUARANTEE – A Guardian Angel for the Extended Home Environment".

The research focuses on

- Social impacts, issues and concerns of ID persons' about safety in their home environment.
- Ethical issues including privacy, informed consent and others arising from the deployment and use of home safety products and services
- Designing a conceptual model for safety solution services for ID people at home

Understanding how a safety service concept can give people a peace of mind and contribute in increasing the quality of lives while simultaneous preventing accidents, is a crucial part of the research. A good safety concept could boost disabled people's confidence, make them feel more secure and would enable them to handle day-to-day activities with more ease. Also, the objective is to design a conceptual service model which delivers a set of safety solutions to the end-user internally or through external collaboration. The eventual design will include a safety solution which involves end-users, technology providers and service providers. The roles of the different actors will be visualized. The service model will involve a non-obtrusive monitoring system with sensing devices to address the needs of the different

stakeholders. The service design approach results in an overall picture of the service experience. This way the design is not only limited to the system, but also for example external service providers are integrated in the design phase.

4. Method

The current user-centered research was carried out to answer questions and give powerful insights about safety and ethics related issues and concerns that will propel the design process. Intellectually disabled people, who are in the focus of the research, live both within assisted living homes and family homes. Assisted living homes are facilities where people with various levels of intellectual disability are supported by nurses. Family homes are regular houses that are adjusted to meet the specific needs of ID people who are capable of semi-independent living. One main difference in a family home is that the professional caregivers are also living there.

The preliminary findings of the ongoing study explained in this paper are based on qualitative interviews with professional caregivers and intellectually disabled persons. The interviews have been video recorded and transcribed for analysis. So far five ID persons, three nursing assistants in assisted living homes and four professional caregivers in family homes were interviewed. The average duration of an interview was 15 minutes for an intellectually disabled person and 30 minutes for a nursing assistant or caregiver. The interviews were carried out in cooperation with Rinnekoti-Säätiö, a foundation for intellectually disabled people in Finland.

The difficulties and frustrations the nurses encountered while providing their care giving tasks were identified. Moreover, their perceptions of safety issues related to people with cognitive disabilities were discussed in the interviews. Ethical issues were also explored. Furthermore, human factors interventions that can alleviate these issues and optimize the comfort and independence of the intellectually disabled were addressed in the interviews.

5. Preliminary findings

The preliminary empirical findings of the present user research relate to the following three aspects.

- Desire to live at home vs. motivation to take care of basic routines independently.
- Using wristband technologies
- Desire for increased social interaction

Desire to live at home vs. motivation to take care of basic routines independently. Our study finds that many ID people could not live alone, or if they could, it was only for short periods. According to one of the nurses in the assisted living homes *"They need assistance in their daily activities, including cooking, taking care of hygiene and using money"*. It is evident that some of the people with intellectual disabilities wish to live independently, at least on some level. One of the participants said *"I would like to live alone but I do not know how to pay my bills because I don't understand the value of money"*. For this to be realized, they need to build their confidence on managing the daily routines without the assistance from the caregivers. On the other hand, it would be important for the caregivers to encourage them to continue practicing their skills. Building motivation is a challenge for people with ID because they have adapted ways of taking daily routines for granted, meaning that somebody will do it for them. As one of the nurses mentioned *"They need motivation even to brush their teeth. If you don't make sure that they do it, they probably won't"*. Indeed, the desire to live alone versus the lack of motivation forms a dilemma that can ultimately rule out otherwise potential individuals from living alone. Living alone would mean more freedom, but also more responsibility to own actions.

Using wristband technologies. One of the main concerns that came up in almost every interview with the caregivers in family homes was that if the participants would live alone, there would be an increased possibility for them to go wandering around. A high percentage of the participants had gone wandering around or ran away from the family homes. One caregiver stated *"The most probable reason to run away could be just to get more attention"*. Putting the reasons beside, it's crucial to recognize and react on these situations where persons go missing. Our interviews proved that most of the interviewees would be willing to wear a wristband or a watch that could signal their location to the caregiver. One of the family home residents said *"It would be good for my mother to know where I am and that she knows everything is okay"*. However, we have no experience yet if they would actually wear such a wristband, as it will be studied in later stage of the project. Some of the ID in the assisted living homes expressed that they do not want to wear a wristband that looks like hospital equipment. To prevent this kind of mindset of being "labeled", the wristband should be designed to look like a normal watch with different functions and appearances.

Desire for increased social interaction. When asking one of our interviewees if she would like to live alone some day, she answered: *"I would love to live alone, with a friend"*. Same kinds of hopes were common among all the participants. When looking at the frequency of social interaction with friends and relatives, it appears that people with disabilities are more isolated than people with no disability: there are more than twice as many people who meet their relatives less than once or twice a month in the population reporting a severe disability than in the population reporting no disability. [10]

6 Conclusion

This article explained an ongoing empirical study aiming to address important issues that need to be taken into consideration when designing safety services for intellectually disabled people living at home. First it introduces the need for research in this specific area. After that, it addresses ethical issues when implementing technological safety solutions in the home environment. Then it explained the ongoing empirical study including a user-centered research and design approach by involving caregivers and intellectually disabled people in the research process. Then, it revealed the research method. Next it discusses preliminary research findings that give an indication of safety related issues and concerns for intellectually disabled people living or aiming to live more independently. The preliminary empirical findings of the present user research relate to the following three aspects: ID persons' desire to live at home vs. motivation to take care of basic routines independently, using wristband technologies, and ID persons' desire for increased social interaction.

References

1. Pomona II project, Health indicators for people with intellectual disabilities, 2008.
2. Finnish Government, Government Resolution on the program for arranging housing and connecting services for the mentally disabled, 2010, http://www.valtioneuvosto.fi/toiminta/periaatepaatokset/periaatepaatos/fi.jsp?oid=286028, viewed 21 Jan 2010.
3. European Commission, People with disabilities, http://ec.europa.eu/social/main.jsp?catId=429, viewed 4.1.2010.
4. Haveman M, Heller T, Lee L, Maaskant M, Shooshtari S, Strydom A. Report on the State of Science on Health Risks and Ageing in People with Intellectual Disabilities, http://www.iassid.org/pdf/State%20of%20Science%20on%20Health%20Risks.pdf, Dortmund, 2009, viewed 8.1.2010.
5. Sherrard J, Tonge B J , Ozanne-Smith J. Injury in young people with intellectual disability: descriptive epidemiology, 2001, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1730696/pdf/v007p00056.pdf, viewed 3.1.2010.
6. Rinnekoti-Säätiö, Foundation's Incident Report, 2009.
7. Disabled Living Foundation, Ethical issues with assistive technology, 2009. http://www.livingmadeeasy.org.uk/scenario.php?csid=43, viewed 9.4.2010.
8. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research, 1979, http://www.uwrf.edu/grants/IRB/BelmontReport.pdf, viewed 09.04.2010.
9. David B. Resnik, Darryl C. Zeldin. Environmental health research on hazards in the home and the duty to warn, Published in final edited form as: Bioethics, 2008 May.

10. European Commission, Disability and Social participation in Europe 2001. http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-AW-01-001/EN/KS-AW-01-OO1-EN.PDF, viewed 5.1.2010.

Attachment 4 Paper 3: Conference paper at ICSTE 2010

Title: Better Technologies and Services for Smart Homes of Disabled People: Empirical Findings from an Explorative Study among Intellectually Disabled

Abstract—The purpose of this article is to increase the knowledge of technologies and services of smart homes for disabled people. There is a clear need for such new knowledge since the number of disabled people is significant and growing in EU, US and worldwide in general. Indeed, new technologies and services of smart homes have the potential to increase effectiveness and efficiency of caring disabled. With right solutions there is a great potential to increase disabled persons' quality of life. The need for the development of such technologies and services increases due to the aging of the population, the increasing cost health care, and the individuals' desire to remain independent in their own homes. This article discusses the concept and nature of disability as well as smart home technologies and services. Based on a qualitative empirical research, this study identifies factors relevant for designing better systems and services for smart homes of intellectually disabled people. Our study found that the attitudes towards using safety technologies are very positive among intellectually disabled. Also, the juxtaposition of safety vs. privacy can be alleviated with right technologies and services. Moreover, there is need for technologies and services to assist intellectually disabled in traffic, protect them from various forms of abuse, and prevent immoderation of pleasure giving activities. Furthermore, there is need for various wristband-based technologies and services. This report is based on the research conducted in ITEA2/GUARANTEE-project, A Guardian Angel for the Extended Home Environment

Keywords-Smart homes, Ambient intelligence, Disabled

1 Introduction

There are at least 650 million people with disabilities worldwide.[1] A growing number of disabled people is expected as a consequence of declining fatalities and stable or increasing non-fatal injuries.[2] Eurostat defines disability as being hampered in daily activities by any physical or mental health problem, illness or disability.[3]

The total number of the population with a long-standing health problem or a disability (LSHPD) in 25 European countries is estimated to account for more than 45 million citizens. These European Union statistics only refer to the population that is 16 to 64 years old. Figure 1 shows the proportions of people in different EU-counties being affected by severe or moderate disabilities. The proportion of people in the EU countries aged 16 and over that reported they were either severely or to some extent hampered in daily activities by any

physical or mental health problem, illness or disability in 1998 ranged from 13% to 40 %. The United States Census reports that 53 million people live in US with one or more chronic conditions that adversely affect their activity level.[4]

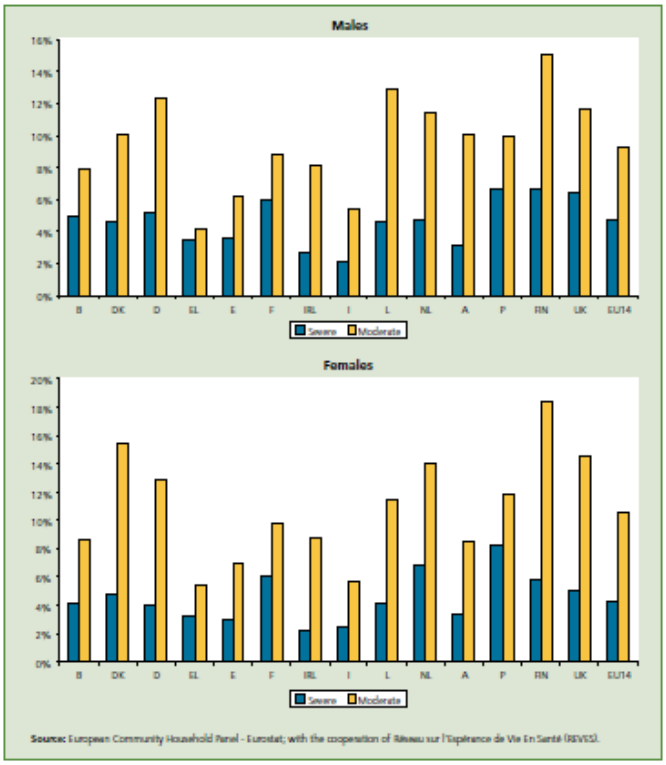


Figure 1. Percentage of people of people aged 16-64 reporting severe or moderate disability in EU , adopted from Eurostat 2002 [5] p. 150

Age is the biggest risk factor for dependency on care (Figure 2). According to a prognosis of the EU-Project FELICIE (Future Elderly Living Conditions in Europe), under the "Healthy Life Gain Scenario" dependency on care until 2030 will increase by 20% for women and by 80% for men after the age of 75.[6]

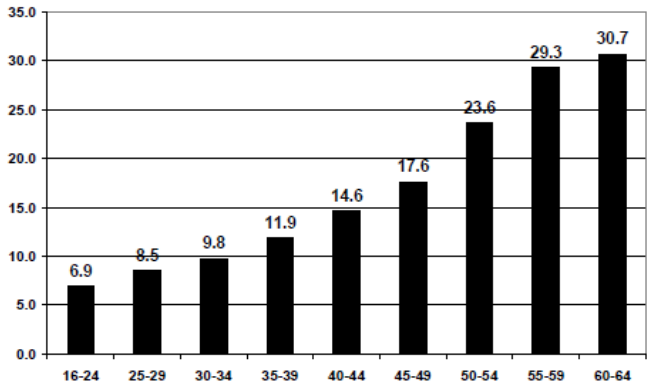


Figure 2. Percentage of disabled in different age groups EU countries adopted from Eurostat [7]

The worldwide population of persons aged 65 and above was an estimated 420 million in 2000, which is a 9.5 million increase from 1999. The worldwide population aged 65 and above is estimated to increase by approximately 550 million to 973 million, increasing from 6.9% to 12.0% worldwide during 2000-2030. This includes the increase from 15.5% to 24.3% in Europe, from 12.6% to 20.3% in North America, from 6.0% to 12.0% in Asia, and from 5.5% to 11.6% in Latin America and the Caribbean. The increase of world's population is explained by two main factors: decline of fertility and increase of life expectancy. Fertility rates have declined in developing countries after 1970 and in developed countries throughout the 20th century. Moreover, in developed countries, the largest gain ever in life expectancy at birth occurred during the 20th century. Life expectancy at birth in developed countries ranges from 76 to 80 years. Life expectancy also has increased in developing countries since 1950, however the amount of increase has varied. [8], [9], [10]

The proportion of elderly people of total population is increasing in many Western countries. Since 1997 the percentage of the European Union population between 65 and 79 years of age has grown from 11.6 to 12.6 in 2008. The population older than 79 years increased from 3.5% to 4.4%. If this trend continues, 30% of the EU-27 population in 2030 will be 65 years or older [11]. In the US, the proportion of the population aged 65 and above is expected to increase from 12.4% in 2000 to 19.6% in 2030. The number of persons aged 65 and above is expected to increase from approximately 35 million in 2000 to an estimated 71 million in 2030. Also, the number of persons aged 80 and above is expected to increase from 9.3 million in 2000 to 19.5 million in 2030.[12], [13]

Indeed, there is an evident need to increase the knowledge of technologies and services of smart homes for disabled people. Both academic and applied knowledge is needed. The present empirical explorative study responds to this need. The purpose of this article is to increase the knowledge of technologies and services of smart homes for disabled people. The report has the following structure. First, it discusses the concept and nature of disability. Next, it discusses smart homes technologies and services. Then, it explains the empirical research method. After, that it reveals the findings of the empirical study. Then, it draws the final conclusions.

2 The concept of Disability

Disability has been defined in several ways. These definitions of disability often vary according to the purpose of the data collection or to different classifications used. Moreover, there are dozens of laws and statutes that contain their own interpretation of disability.[14] Three main perspectives can be distinguished to understand the nature disability: medical, economic and socio-political. *The medical perspective* defines disability in terms of functional impairments. The person with a disability is viewed as an entity to be fixed, or cured by

experts. According to Barton and sources referred by her, the medical perspective is the most disempowering of all the perspectives but remains a very strong, very stigmatizing perspective on disability.[15] The economic perspective emphasizes the vocational and employability problems of people with disabilities. Individuals with disabilities are viewed as less than full participants in the market economy. The socio-political perspective is the only approach that does not depend on the intervention of professionals to address, or treat, the disability. According to Barton and sources referred by her (ibid.), the socio-political approach is at the core of the independent living philosophy. In this approach, disability is a product of a person's interactions with the environment. The environment is seen as the "disabling" obstacle, not the individual. Examples of socio-political approach include attitudes toward people with disabilities, architectural barriers, and inaccessible homes and services. Professionals act in a consultancy role, and treatment goal setting is individualized and driven, when possible, by the client.[16], [17], [18]

According to ADA Americans with Disability Act, "disability" means, with respect to an individual 1) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; 2) a record of such an impairment; 3) being regarded as having such an impairment.[19] ADA also provides the term "qualified individual with a disability" which means an individual with a disability who, with or without reasonable modifications to rules, policies, or practices, the removal of architectural, communication, or transportation barriers, or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.[20]

According to Steinmetz, United States Census defines communication, physical, and mental disability as follows.[21] People 15 and older are identified as having a disability in a communication domain if they meet any of these criteria: (a) have difficulty seeing, hearing, or speaking; (b) are blind or deaf; or (c) identify one or more related conditions as the cause of an activity limitation (blindness or vision problem, deafness of hearing problem, or speech disorder). People 15 and older are identified as having a disability in a physical domain if they meet any of the following criteria: (a) use a wheelchair, cane, crutches, or walker; (b) have difficulty with one or more functional activities (i.e.—walking a quarter of a mile, climbing a flight of stairs, lifting a ten pound bag of groceries, grasping objects, getting in or out of bed); or (c) identify one or more related conditions as the cause of a reported activity limitation (arthritis or rheumatism; back or spine problems; broken bone or fracture; cancer; cerebral palsy; diabetes; epilepsy; head or spinal cord injury; heart trouble or hardening of arteries; hernia or rupture; high blood pressure; kidney problems; lung or respiratory problems; missing legs, arms, feet, hands, or fingers; paralysis; stiffness or deformity of legs, arms, feet, or hands; stomach/digestive problems; stroke; thyroid problems; or tumor, cyst, or growth). Finally, people 15 and older are identified as having a disability in a mental domain if they meet any of the following criteria: (a) have one or more specified conditions

(a learning disability, mental retardation or another developmental disability, Alzheimer's disease, or some type of mental or emotional condition); (b) have any other mental or emotional condition that seriously interfered with everyday activities (frequently depressed or anxious, trouble getting along with others, trouble concentrating, or trouble coping with day-to-day stress); (c) have difficulty managing money/bills; or (d) identify one or more related conditions as the cause of a reported activity limitation (attention deficit hyperactivity disorder; autism; learning disability; mental or emotional problems; mental retardation; or senility, dementia, or Alzheimer's).

Disabled person is defined by Centers for Disease Control as an individual having limitations in physical or mental function, caused by one or more health conditions, in carrying out socially defined tasks and roles that individuals generally are expected to be able to do.[22]

The WHO World Health Organization's definition for disability is based on body functions and body structures.[23] Impairment in bodily structure or function, on the other hand, is understood to involve an anomaly, defect, loss or other significant deviation from certain generally accepted population standards, which may fluctuate over time.

National Organization on Disability define person to be disabled 1) if he or she has a physical disability, a seeing, hearing, or speech impairment, and emotional or mental disability, or a learning disability; 2) if he or she has a disability or health problem that prevents from participating fully in work, school, or other activities; or 3) if he or she considers himself or herself disabled, or says that other people would consider him or her disabled.[24]

TABLE I. DIMENSIONS OF DISABILITIES

Type of impairment	**Description**	**Difficulties in one of more of the following areas:**
Mobility impairments	Varying levels of physical mobility restrictions, affecting legs, feet, back, neck, arms or hands	- physical and motor tasks - independent movements - performing basic life functions
Sensory impairments	Capacity to see is limited or absent Completely deaf or are hard of hearing	- reduced performance in tasks requiring clear vision - difficulties with written communication - difficulties with understanding information presented visually - reduced performance in tasks requiring sharp hearing - difficulties with oral

		communication - difficulties in understanding auditorally-presented information
Communication impairments	Limited, impaired, or delayed capacities to use expressive and/or receptive language	- general speech capabilities, such as articulation - problems with conveying, understanding, or using spoken, written, or symbolic language
Intellectual/ mental impairments	Lifelong illnesses with multiple aetiologies that result in a behavioural disorder	- slower rate of learning - disorganised patterns of learning - difficulties with adaptive behaviour - difficulties understanding abstract concepts - limited control of cognitive functioning - problems with sensory, motor and speech skills - restricted basic life functions
Hidden impairments	Variety of illnesses	- heart problems - blood pressure or circulation problems - breathing difficulties - problems with stomach, liver or kidneys - problems to control the level of sugar in the blood (diabetes) - disorder of the central nervous systems (epilepsy)

Source: in D. Buhalis et al., 2005, [25] p. 11, based on DEO [26]

According to Knoblauch and Sorenson, IDEA Individuals with Disabilities Education Act addresses the disability infants and children. “Child with a disability” means a child: “with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and who, by reason thereof, needs special education and related services.[27]

Several types of disabling conditions can arise from a variety of impairments ranging from those acquired at birth to those which arise as part of the ageing process, accidents or illnesses. The different types of disabling conditions usually come under a number of

commonly used descriptive headings or terms. They cover mobility, sensory and communication impairments, intellectual impairments and mental health disorders as well as hidden impairments in forms of health problems (Table I).[28] Figure 3 shows the distribution of these major types of impairments and health problems within 25 EU countries for the population that is 16 to 64 years old. Figure 4 shows a more detailed picture by splitting these main categories into more specific subcategories.

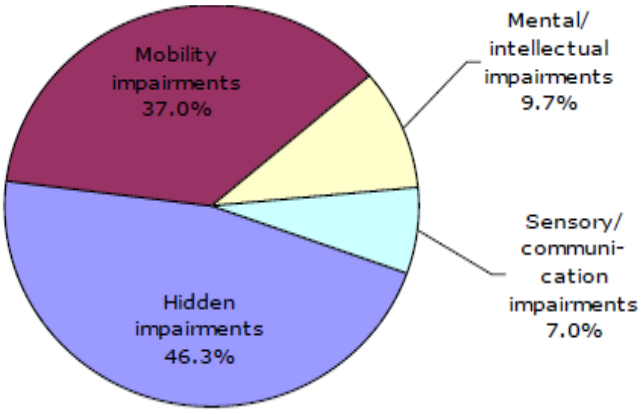


Figure 3. Distribution of major types of disabilities in EU, adopted from Buhalis et al., p. 38 [29] based on source Eurostat 2005 [30]

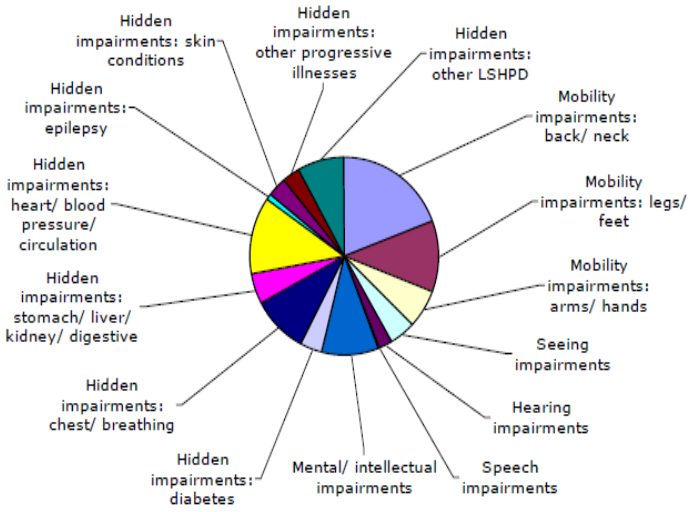


Figure 3. Distribution of subcategories of disabilities in EU, adopted from Buhalis et al., p. 39 [31] based on source Eurostat 2005 [32]

Indeed, the concept of disability includes both the medical and social aspects. The discussion by the Union of the Physically Impaired Against Segregation and The Disability Alliance distinguish between “impairment” and “disability.” They define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body. Disability, on the other hand, is understood as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social

activities.[33] Thus, according to this definition, disability refers to discrimination of impaired persons in society, and impairment to a person's physical or cognitive limitation or inability.[34] The social aspect of disability has, for example, the following consequence. Many individuals do not want to identify themselves as disabled. The term disabled has a negative tone in many cultures and societies. Many people fear that if they are called "disabled," others will see them as wholly disabled and fail to recognise their remaining abilities.[35]

3 Smart Homes

Technologies and services of Smart Homes

Living independently can be seen as a complex set of functions and activities that are performed in a living environment. A house is an example of living environment. Through time and in between different cultures the performance of these activities varies, in means, quantity and quality. Living has an environmental, protectional, and social dimension. These dimensions are the result of the interaction between person, environment and occupation. An example of environmental dimension is a house in a street. The protectional dimension refers, for example, to the barriers against intruders. The social dimension of independent living means, for example having a meeting place with privacy.[36], [37]
"Smart Home" refers to a residence equipped with technology that allows monitoring of its inhabitants and/or encourages independence and the maintenance of good health.[38] Smart environments assist with several functions, such as remote health monitoring and intervention. The need for the development of such technologies increases due to the aging of the population, the cost of formal health care, and the importance that individuals place on remaining independent in their own home.[39]
Smart Homes contribute to caring disabled people living alone at home, the elderly, and people with chronic illness. This approach to health assessment can improve the quality and variety of information transmitted to the clinician. Measures of physiological signs and behavioral patterns can be translated into accurate predictors of health risk. This can happen already at an early stage, and can be combined with alarm-triggering systems as a technical platform to initiate appropriate action. Smart Homes and Telecare can provide the infrastructure for coordinating multidisciplinary care outside the hospital. This can include, for example scheduling visits with health staff and community health workers, automating collection of clinical findings and test results.[40] As different people have varying needs, the provision of assistance should be tailored to each individual [41].
The term Electronic Aids to Daily Living (EADL) closely relates to the Smart Home concept. It refers to devices that are used to access, operate, and control electrical appliances for comfort, communication, leisure, and personal security.[42] This technology allows persons with a severe physical disability such as spinal cord injury to control a wide variety of

household and workplace appliances, so that they can be independent of assistance from family members or other caregivers. With help of this technology, users can use devices necessary for daily living with a variety of control methods such as single switch, touch screen, or voice. EADL devices are typically used to operate the phone, TV, stereo, fan and lights.[43], [44], [45]

The term Ambient Intelligence (AmI) was introduced by the European Union to refer to a potential future in which we will be surrounded by intelligent objects and in which the environment will recognize the presence of persons and will respond to it in an undetectable manner.[46] Ambient Intelligence is a discipline that brings intelligence to our everyday environments and makes those environments sensitive to us. The research of this area builds upon advances in sensors and sensor networks, pervasive computing, and artificial intelligence. Ambient intelligence systems are sensitive, responsive, and adaptive. This emphasizes the dependence on context-aware computing.[47] Ambient Intelligence is based on the presence of a digital environment that is sensitive, adaptive, and responsive to the presence of people.[48] In an AmI environment, people are surrounded with networks of embedded intelligent devices that can sense their state, anticipate, and perhaps adapt to their needs.[49] Such a digital environment proactively, but sensibly, assists people in their daily lives.[50] Ambient Intelligence is a vision of a future daily life and contains the assumption that intelligent technology should disappear into our environment to bring humans an easy and entertaining life [51].
Sensing, reasoning, and acting are basic functions of Ambient Intelligence [52].

- Sensing. The use of sensors is vital for AmI, since they are the key that link available computational power with physical applications. They are used to position measurement, for detection of chemicals and humidity sensing, and to determine readings for light, radiation, temperature, sound, strain, pressure, position, velocity, and direction, and physiological sensing to support health monitoring. [53] Sensors should be small; they may be wireless, and often use power from batteries. Environmental monitoring, situational awareness, and structural safety monitoring are typical examples of sensor application areas.
- Reasoning. Sensing and acting provide links between intelligent algorithms and the real world where they operate. To make these algorithms responsive, adaptive, and beneficial to users, a number of types of reasoning must take place. Reasoning covers user modelling, activity prediction and recognition, decision making, and spatial-temporal reasoning.
- Acting. Ambient Intelligence systems tie reasoning to the real world through sensing and acting. Intelligent and assistive devices provide a mechanism by which these systems can executive actions and affect the system user, for example an elderly person. Another mechanism for acting is through robots. Robots are able to provide

an increasing range of assistive tasks to support Ambient Intelligence. Robots can monitor the vital signs of their masters, provide conversational stimulation, exhibit more human-like emotions and expressions than in the past and even influence human decision [54].

Desiging Smart Home technologies and services

Dewsbury, Clarke, Rouncefield, Sommerville, Taylor, and Edge suggested an approach for assessing technologies to support people in the home. The basic questions and issues to be addressed in their approach are summarized below.[55]

1. *Stakeholder identification and needs*. It is vital to identify all the relevant stakeholders for the particular case and their needs. Stakeholders may entail members of family, care staff, care managers, social work, housing and health authorities, funding bodies, building societies, advocates, emergency services etc. It is important to consider the needs of carers, residents, and other stakeholders within the same view and not as separate entities. This should be mediated by the cost/budget of the project.
2. *Budgetary constraints*. Who is paying? For what are they paying? What is being paid for in the design? What budgetary constraints are there?
3. *Accessibility to services and technologies*.
   a) *In internal spaces*. Are they accessible? Are they comfortable, convenient, easy to use and enjoy? Are they meeting the needs of the residents for privacy, independence and rehabilitation? Does the technology fit aesthetically with the users' views of the living spaces? Do they meet the needs of the carers: privacy, security?
   b) *External Spaces and gardens*. Is this space secure and safe? Is space accessible? Is it attractive? Is it maintainable? Does the user occupy this space?
4. *Residential structure*. House or flat or multi occupancy dwelling? How many rooms/levels/floors are accessible to resident(s)? How many floors/levels are there? What are the routines and activity patterns of the residents? Does the home meet accessibility criteria?
5. *Technology system specification*.
   a) *Use case and basic architecture of the system*. Are alternative non high-tech solutions more appropriate? What systems can enable the carer and residents and which are definitely not suitable for consideration? Is there to be one major system and manufacturer to be used throughout the design or a number of different ones? How is the system going to benefit the carer(s) and resident(s)? Where are the electrical points (switches and sockets) to be placed? Are they at the appropriate height and easily accessible? Where are the control units to be placed? How many different systems are needed to be combined together in the overall design? Are

there any special considerations that are required within individual designs? How much are these likely to cost? Are they feasible? Can they interface with the main system design?

b) *Making usable, interactive, safe and secure for residents and carers*. What form of alerting system is required (sound, visual, tactile etc)? What prioritisation do each of the potential alerts require? Who is to access and act on the alerts? What safety features are required (such as back ups)? What support systems are required? Are the user interfaces clear and easy to use? What rehabilitative systems are required? Does the user interface provide meaningful feedback to the user so that it is understandable? Does the system augment the residents and staff/carers? Are the systems not likely to add to confusion? Is the system easy to learn? Is the system self-evident? Can the system be upgraded? Are automated tasks doing what they should do and measuring what they should measure? Will the system do what everyone expects the system to do, no more and no less? A false conception of what the technology offers is poor design.

In addition to technology development, measuring and assessing the effectiveness and efficiency of smart home technologies is important. This is important for development of profitable business models of services and products of Smart Homes. Assessing efficiency and effectiveness of smart homes is also important for ensuring that user needs are the driving force of technology development. It is also important for policy makers and financers of health care systems who require relevant information for their decision making process.

Smart homes can be useful by enhancing the quality of life for people whose life is limited by their domestic environment. The design process is something that requires needs to be considered within a framework of barrier free design. However, technology for technology's sake like inappropriate design can be debilitating and disempowering.[56] The research has emphasized the importance in addressing the outcomes of assistive technology from the users' perspectives.[57] [58] This can help to justify the costs of this technology and influence policy regarding funding. [59] [60] DeRyter suggested five dimensions for evaluating assistive technology: (1) clinical results, (2) functional status, (3) quality of life, (4) satisfaction, and (5) cost.[61]

4 Research Method

The empirical study of this article is based on qualitative research methodology. The data were gathered from persons who all were intellectually disabled. Many of them had some kind of physical disability as well. Thus, instead of "disabled" we call them here "intellectually disabled" (referred as ID in the following). They were living in homes on their own, semi assisted living homes, and in family homes. Data were also gathered from the nurses and relatives of ID in a focus group interview. 13 ID persons and 11 nurses and relatives were interviewed. The interviews were video recorded. All empirical data were gathered from

intellectually disabled living in Finnish Rinnekotisäätiö's facilities as well as from their nurses and relatives. Rinnekotisäätiö is the Foundation for Intellectually Disabled in Finland. The data were later analyzed by using affinity diagram method.[62], [63] More specifically, the data were analyzed by grouping empirical clues from the data into emergent higher abstraction level categories in a joint meeting of researchers. In other words, clues from the interviews were extracted from the original context and organized again into groups or categories based on their similarities. These categories are later called as "factors." No software was used in the analysis. Based on the analysis, several factors were identified relevant for designing better technologies and services for smart homes of ID people.

5 Empirical Findings

Several factors emerged from our empirical study relevant for designing better technologies and services for smart homes of ID people. They are explained in the following. The factors are:

- Positive attitudes of intellectually disabled towards using safety technologies and services
- The juxtaposition of safety vs. privacy can be alleviated with right technologies and services
- Need for technologies and services to assist in traffic
- Need for technologies and services protecting intellectually disabled against abuse
- Need for technologies and services preventing immoderation of pleasure giving activities
- Need for wristband-based technologies and services

Positive attitudes of intellectually disabled towards using safety technologies and services. Our study suggests that the attitudes towards using safety technologies are very positive among ID. Many of them realize that they need help in some situations and are willing to use or wear safety devices. Even though the interviewed persons did not know exactly what such services or devices might be, they are likely to receive a good reception. Especially, the use of remote assist was of high interest to the ID themselves as well as carers and nurses.
The juxtaposition of safety vs. privacy can be alleviated with right technologies and services. Often, ID person's safety and privacy are in juxtaposition. For example, the condition of an ID person has to be checked during the night for reasons such as diabetes or epilepsy. This is often perceived to be uncomfortable and invasive towards the privacy of an ID person. Of course, most ID persons understand that their safety is more important than privacy. Indeed, in several cases, the monitoring technology can be used to alleviate the contradiction between safety and privacy. Monitoring and alarm systems can enhance the privacy of the individuals by reducing or removing the need for personal control visits of carers. In many

cases, the use of monitoring technology is considered to be ethically problematic. Our findings suggest that, despite ethical considerations, right monitoring technology has the potential to increase an ID persons' privacy without decreasing their safety.

Need for technologies and services to assist intellectually disabled in traffic. Our study suggests that traffic is no major challenge for people who have lighter disability. Many lighter disabled are able to use public transportation without any problems, particularly if the route is familiar. However, traffic causes problems to persons with more difficult disabilities. The behavior in traffic is a significant concern for the ID persons, in particular. Lack of concentration or getting distracted are the main reasons that could lead to dangerous situations. This indicates the clear need for technologies and services to assist them in traffic.

Need for technologies and services protecting intellectually disabled against abuse. Our findings suggest that ID persons are particularly vulnerable for abuse. This may include sexual abuse, being a victim of a fraud, or getting involved with bad company and criminal activity. It is not uncommon for an ID person to get in a situation where he acts against his own will or believe, just trying to please the other person. Our study found cases where outsiders have appeared to the area of the assisted living homes, and in the night time tried to convince the female residents to join them. ID persons have not been able to recognize these untrustworthy people causes a real danger. Furthermore, the fact that they do not understand the value of money and cannot count makes them vulnerable for fraud. Thus, there is an evident need for services and technologies that protect them against abuse.

Need for technologies and services preventing immoderation of pleasure giving activities. Our study suggests that many ID persons are unable to stop pleasure giving activities. Such pleasurable activities include eating, drinking, socializing with friends, and using the Internet. For example, our empirical material included a case where an ID person did not know when to leave from friends in time, and therefore she became so fatigued that her mental condition collapsed completely. Many ID people, if not controlled, eat just candies and fast food, and drink coffee. Overweight is a real problem amongst people with ID. Obesity causes various health problems which can, in the long run, be fatal. Sometimes the nursing homes have to use locks on the fridges, so that they would not have access to the food at all times. Indeed, there is an obvious need for services and technologies that help in controlling pleasure giving activities of ID persons.

Need for wristband-based technologies and services. Many ID persons are able to go outside their own homes or nursing homes. They often like to be outside of their residence alone and independently. They go to see their friends or just spend time in the city. They may also be able to go to work with public transportation. ID persons can manage nicely as long as they face familiar routines and situations. However, new situations can cause them to feel anxiety and fear. For example, if the person is used to go to work every day with the same bus but one day the bus has already gone, and he does not realize to wait for the next one, he might

leave and do something totally unexpected and harmful. In some cases it is possible that an ID person gets disoriented and loses sense of time and place. This might happen in unfamiliar surroundings where the person may panic. Furthermore, ID people may feel their physical security to be threatened by other people outside their own home. The situations causing this fear were occurring, based on our study, typically during the evening or night time when they were walking alone. They may feel threatened and therefore try to avoid for example groups of young people. Clearly, there is a need for various wristband-based technologies that help the people with ID to cope with new situations outside home as well as to increase their security.

Conclusions

The purpose of this article was to increase the knowledge of technologies and services of smart homes for disabled people. There is a clear need for such new knowledge, since the number of disabled people is significant and increasing in EU, US and worldwide in general. Indeed, new technologies and services of smart homes have the potential to increase effectiveness and efficiency of nursing disabled as well as increasing their quality of life. First, based on the literature, this article discussed the concept and nature of disability. Next, also based on the earlier literature, it discussed smart homes technologies and services, Then, it explained the qualitative empirical research method used in this study. After that, it revealed the empirical findings, as follows.

As a result, this study identified several factors relevant for designing better technologies and services for smart homes of intellectually disabled people. Our study found that the attitudes towards using safety technologies are very positive among the persons with ID. Also, the juxtaposition of safety vs. privacy can be alleviated with right technologies and services. Moreover, there is need for technologies and services to assist ID in traffic, protect them from various forms of abuse, and prevent immoderation of pleasure giving activities. Furthermore, our study suggests that there is need for various wristband-based technologies and services.

References

[1] UN Nations Convention on Rights of Persons with Disabilities, 2007.

[2] R. Bauer, K. Steiner. Injuries in the European Union, Vienna, 2009. https//webgate.ec.europa.eu/idb/documents/2009-IDB-Report_screen.pdf, viewed 6 Jan 2010.

[3] EUROSTAT. Health Statistics. Key Data on Health 2002. http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-08-02-002/EN/KS-08-02-002-EN.PDF, viewed 20 May 2010

[4] E. Steinmetz, Household economic studies current population reports P70-107, Americans with disabilities: 2002, 2002.

[5] EUROSTAT. Health Statistics. Key Data on Health 2002.

http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-08-02-002/EN/KS-08-02-002-EN.PDF

[6] R. Bauer and K. Steiner, Injuries in the European Union, Vienna, 2009. https://webgate.ec.europa.eu/idb/documents/2009-IDB-Report_screen.pdf, viewed 6 Jan 2010.

[7] Eurostat, Employment of Disabled People in Europa in 2002, Catalogue number: KS-NK-03-026-EN-N, 2003. http://cms.horus.be/files/99909/MediaArchive/pdf/Emplyment_people_EU25-EN.pdf, Viewed 21 May 2010

[8] Centers for Disease Control and Prevention, 2003. Public Health and Aging: Trends in Aging. United States and Worldwide. MMWR Weekly, Feb 14, 52(06), 101-106. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5206a2.htm, viewed 9 Feb 2010.

[9] K. Kinsella K and V. Velkoff, U.S. Census Bureau. An Aging World: 2001. Washington, DC: U.S. Government Printing Office, 2001; series P95/01-1.

[10] U.S. Census Bureau, International database. Table 094. Midyear population, by age and sex. http://www.census.gov/population/www/projections/natdet-D1A.html, viewed 9 Feb 2010

[11] R. Bauer, K. Steiner. Injuries in the European Union, Vienna, 2009. https://webgate.ec.europa.eu/idb/documents/2009-IDB-Report_screen.pdf, viewed 6 Jan 2010.

[12] Centers for Disease Control and Prevention, 2003. Public Health and Aging: Trends in Aging. United States and Worldwide. MMWR Weekly, Feb 14, 52(06), 101-106. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5206a2.htm, viewed 9 Feb 2010.

[13] U.S. Census Bureau. International database. Table 094. Midyear population, by age and sex. Available at http://www.census.gov/population/www/projections/natdet-D1A.html, viewed 9 Feb 2010.

[14] B. Barton, "Dreams Deferred: Disability Definitions, Data, Models, and Perspectives," Journal of Sociology & Social Welfare, Volume XXXVI, No. 4, Dec. 2009, pp. 13-24.

[15] B. Barton, "Dreams Deferred: Disability Definitions, Data, Models, and Perspectives," Journal of Sociology & Social Welfare, Volume XXXVI, No. 4, p. 22.

[16] H. Hahn, "Changing perception of disability and the future of rehabilitation," in Social influences in rehabilitation planning: Blueprint for the 21st century, A report of the Ninth Mary E. Switzer Memorial Seminar, Alexandria, VA: National Rehabilitation Association, L. Perlman & G. Austin, Eds., 1985, pp. 53-64.

[17] R. Marinelli, R. and A. Dell Orto, The psychological and social impact of disability (4th ed.), New York, Springer Publishing Company, 1999.

[18] B. Barton, "Dreams Deferred: Disability Definitions, Data, Models, and Perspectives," Journal of Sociology & Social Welfare, Volume XXXVI, No. 4, pp. 13-24.

[19] Americans with Disabilities Act, Sec. 12102, Definition of disability. 2008.

[20] CESSI, Federal statutory definitions of disability, 2003. http://www.icdr.us/documents/definitions.htm#table1, Viewed 21 May 2010

[21] E. Steinmetz, Household economic studies current population reports P70-107, Americans with disabilities: 2002, 2002.

[22] Centers for Disease Control, 2009.

[23] World Health Organization. International Classification of Functioning, Disability and Health (ICF), 2009.
www.who.int/classifications/icf/en
Viewed 21 May 2010

[24] National Organization on Disability, Landmark disability survey finds pervasive disadvantages, 2004.

[25] D. Buhalis, V. Eichhorn, E. Michopoulou and G. Miller, Accessibility Market and Stakeholder Analysis, One-Stop-Shop for Accessible Tourism in Europe, OSSATE, University of Surrey, 2005, p. 11
http://www.ossate.org/doc_resources/OSSATE_Market&Stakeholder%20Analysis_Public_Version_Fina..pdf

[26] DEO Department of Education Massachusetts, Disability Definitions and Related Links, last updated 2000.
http://www.doe.mass.edu/sped/definitions.html, viewed 21 May 2010

[27] B. Knoblauch and B. Sorenson, (1998). IDEA's definition of disabilities, ERIC Digest E560, ED429396, 1998.

[28] D. Buhalis, V. Eichhorn, E. Michopoulou and G. Miller, Accessibility Market and Stakeholder Analysis, One-Stop-Shop for Accessible Tourism in Europe, OSSATE, University of Surrey, 2005.
http://www.ossate.org/doc_resources/OSSATE_Market&Stakeholder%20Analysis_Public_Version_Fina..pdf
viewed 20 May 2010

[29] D. Buhalis, V. Eichhorn, E. Michopoulou and G. Miller, Accessibility Market and Stakeholder Analysis, One-Stop-Shop for Accessible Tourism in Europe, OSSATE, University of Surrey, 2005, p. 38
http://www.ossate.org/doc_resources/OSSATE_Market&Stakeholder%20Analysis_Public_Version_Fina..pdf
viewed 20 May 2010

[30] Eurostat, Population and Social Conditions: Percentual Distribution of Types of Disability by Sex and Age Group, 2005.

[31] D. Buhalis, V. Eichhorn, E. Michopoulou and G. Miller, Accessibility Market and Stakeholder Analysis, One-Stop-Shop for Accessible Tourism in Europe, OSSATE, University of Surrey, 2005, p. 39
http://www.ossate.org/doc_resources/OSSATE_Market&Stakeholder%20Analysis_Public_Version_Fina..pdf
viewed 20 May 2010

[32] Eurostat, Population and Social Conditions: Percentual Distribution of Types of Disability by Sex and Age Group, 2005.

[33] Union of the Physically Impaired Against Segregation & Disability Alliance, Fundamental Principles of Disability, UK, 1975.
http://www.leeds.ac.uk/disability-studies/archiveuk/UPIAS/fundamental%20principles.pdf, viewed 20 May 2010

[34] J. Burnett and H. Bender Baker, "Assessing the Traver-Related Behavious of the Mobility-Disabled People," Journal of Travel Research, Vol 40, No. 1, pp. 4-11, 2001.

[35] S. Wendell, The Rejected Body: Feminist Philosophical Reflections on Disability, New York, Routledge, 1996.

[36] C. G. Willes, "Smart Homes," Technology and Disability , vol.15, 2003, pp. 163–164.

[37] P. Fougeyrollas, L. Noreau, Bergeron, R. Cloutier, S. Dion and G. St. Michel, Social consequences of long term impairments and disabilities: Conceptual approach and assessment of handicap, Int. J. Rehab. Research, vol. 21, 1998, 127–141.

[38] M. Chan, E. Campo, D. Estève and J-Y. Fourniols, J-Y., "Smart homes – Current Features and future perspectives," Maturitas, vol. 64, 2009, pp. 90-97,.

[39] P. Rashidi, D. Cook, L. Holder, and M. SchmitterEdgecombe, M., "Discovering activities to recognize and track in a smart environment," IEEE Transactions on Knowledge and Data Engineering, forthcoming. http://www.eecs.wsu.edu/~cook/pubs/tkde10.pdf, viewed 9 Feb 2010

[40] B.G. Celler, N.H. Lovell and J. Basilakis, " Using Information technology to improve the management of chronic disease," Medical Journal of Australia, vol. 179 no. 5, 2003, pp. 242–6.

[41] M. Chan, E. Campo, D. Estève and J-Y. Fourniols, J-Y., "Smart homes – Current Features and future perspectives," Maturitas, vol. 64, 2009, pp. 90-97, 2009.

[42] M. Lange, Electronic aids to daily living, Rehabilitation Report, Oct 1999, pp. 24-27.

[43] W.C. Mann, Use of environmental control devices by elderly nursing home patients, Assistive Technology, vo.l 4 no. 2, 1992, pp. 60–65.

[44] D.C. Symington, D.W. Lywood, J.S. Lawson and J. MacLean, Environmental control systems in chronic care hospitals and nursing homes, Archives of Physical Medicine and Rehabilitation,
vol. 67 no. 5, 1986, pp. 322–325

[45] W.W. von Maltzahn, M. Daphtary and R.L. Roa, Usage patterns of environmental control units by severity disabled individuals in their homes, IEEE Trans Rehabilitation Engineering, vol. 3 no. 2, 1995, pp. 222–227.

[46] IST Advisory Group, Scenarios for ambient intelligence in 2010, European Commission, Community Research, 2001. ftp://ftp.cordis.europa.eu/pub/ist/docs/istagscenarios2010.pdf, viewed 6 Feb 2010

[47] D.J. Cook, J.C. Augusto, and V.R. Jakkula, forthcoming, "Ambient intelligence: Technologies, applications, and opportunities," Journal of Pervasive and Mobile Computing, forthcoming. http://www.eecs.wsu.edu/~cook/pubs/pmc10.pdf, viewed 9 Feb 2010

[48] Phillips Research, Ambient intelligence: Changing lives for the better, 2007. www.research.phillips.com/.

[49] A. Vasilakos and W. Pedrycz, “Ambient Intelligence, Wireless Networking, and Ubiquitous Computing,” Artech House Publishers, 2006.

[50] J.C. Augusto and P. McCullah, ”Ambient intelligence: Concepts and applications,” International Journal on Computer Science and Information Systems, 4(1), pp. 1-28, 2007.

[51] C.K.M. Crutzen, ”Invisibility and the meaning of ambient intelligence,” International Review of Information Ethics, 6, pp. 1-11, 2006.

[52] D.J. Cook, J.C. Augusto and V.R. Jakkula, “Ambient intelligence: Technologies, applications, and opportunities,” Journal of Pervasive and Mobile Computing, forthcoming. http://www.eecs.wsu.edu/~cook/pubs/pmc10.pdf, viewed 9 Feb 2010

[53] B. Naja, K. Aminian and A. Paraschiv-Ionescu, F. Loew, C. Bula and P. Robert, P., “Ambulatory system for human motion analysis using a kinematic sensor: Monitoring of daily physical activity in the elderly,” IEEE Transactions on Biomedical Engineering, 50(6), pp. 711-723, 2003.

[54] C. Brezeal and B. Scassellati, “A context-dependent attention system for a social robot,” Proceedings of the International Joint Conference on Artificial Intelligence, 1146-1151, 1999.

[55] G. Dewsbury, K. Clarke, M. Rouncefield, I. Sommerville, B. Taylor, and M. Edge, “Designing Acceptable ‘Smart’ Home Technology to Support People in the Home, Technology and Disability, vol. 15, 2003, pp. 191-199.

[56] G. Dewsbury, B. Taylor and M. Edge, The Process of Designing Appropriate Smart Homes: Including the user in the design, A paper presented to the Workshop on Ubiquitous Computing in Domestic Environments, Nottingham University, 13–14th September 2001.

[57] G.E. Jacques, S. Ryan, S. Naumann, M. Milner and W.L. Cleghorn, Application of quality function deployment in rehabilitation engineering, IEEE Trans Rehabilitation Engineering, vol. 2, 1994, pp. 158–164.

[58] B. Philips and H. Zhao, Predictors of assistive technology abandonment, Assistive Technology, vol. 5, 1993, pp. 36–45.

[59] R. Andrich, M. Ferrario and M. Moi, A model of cost-outcome analysis for assistive technology, Disability Rehabilitation, vol. 20 no. 1, 1998, pp. 1–24.

[60] N.B. Oldridge, Outcomes measurement: health state preferences and economic evaluation, Assistive Technology, vol. 8 no. 2, 1996, pp. 94–102.

[61] F. DeRuyter, Evaluating outcomes in assistive technology: do we understand the commitment? Assistive Technology, vol. 7, 1995, pp. 3–8.

[62] C. Plain. “Build an Affinity for K-J Method,” Quality Progress, Vol. 40, No. 3, 2007, p. 88.

[63] D. Mohamedally and P. Zaphiris, “Categorization Constructionist Assessment with Software-based Affinity Diagramming,” International Journal of Human-Computer Interaction, Vol. 25 No. 1, pp. 24-48.

Attachment 5 Paper 4: Conference paper at SEDE 2010

Title: 'Designing services and systems for safety of elderly people at home: an ongoing empirical study'

ABSTRACT

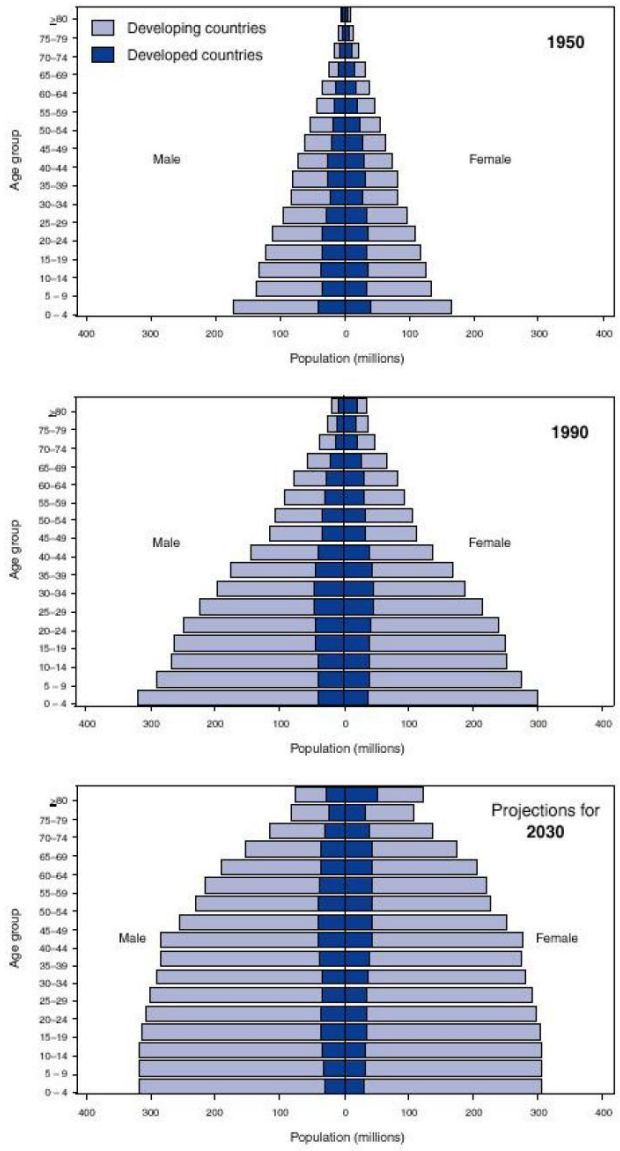
This article reports on an ongoing study aiming at designing services and systems for safety of elderly people at home. There is an evident and urgent need to increase the knowledge of this area. Indeed, both academic as well as practical knowledge is needed. First, this article explains why the research and development in this area is needed. Then, it discusses technologies to enhance the safety of elderly in their homes. Next, it discusses Smart Homes and Ambient Intelligence. After that, it explains the ongoing empirical study. Then, it draws the final conclusions.

1 INTRODUCTION

The proportion of elderly people of total population is increasing in several Western countries. For example, since 1997 the percentage of the European Union population between 65 and 79 years of age has grown from 11.6 to 12.6 in 2008. The population older than 79 years from 3.5 to 4.4. If this trend continues, 30% of the EU-27 population in 2030 will be 65 years or olderIn the US, the proportion of the population aged 65 and above is expected to increase from 12.4% in 2000 to 19.6% in 2030. The number of persons aged 65 and above is expected to increase from approximately 35 million in 2000 to an estimated 71 million in 2030. The number of persons aged 80 and above is expected to increase from 9.3 million in 2000 to 19.5 million in 2030.[1] [2] Similarly, it was estimated that, for example in Australia, the proportion of elderly people will double by 2040 [3].

In 2000, the worldwide population of persons aged 65 and above was an estimated 420 million. The pattern of development is shown in Figure 1. This is a 9.5 million increase from 1999. During 2000-2030, the worldwide population aged 65 and above is estimated to increase by approximately 550 million to 973 million, increasing from 6.9% to 12.0% worldwide. This includes the increase from 15.5% to 24.3% in Europe, from 12.6% to 20.3% in North America, from 6.0% to 12.0% in Asia, and from 5.5% to 11.6% in Latin America and the Caribbean. Two main factors explain the increase of world's population, namely declines in fertility and increases in life expectancy. Fertility rates have declined in developing countries after 1970 and in developed countries throughout the 20th century. Moreover, in developed countries, the largest gain ever in life expectancy at birth occurred during the 20th century. Life

expectancy at birth in developed countries now ranges from 76 to 80 years. Life expectancy also has increased in developing countries since 1950, although the amount of increase varied.[4] [5] [6]



Source: United Nations, 1999, and U.S. Bureau of the Census, 2000.

Figure 1 Population age distribution for developing and developed countries by age group and sex - worldwide 1950, 1990, and 2030 (adopted from MMWR Weekly 2003, p. 6 [7])

An increasing number of older people need long-term care and services, but do not meet the criteria of or cannot afford to nursing homes, and consequently receive the caring at home [8] [9]. Long-term care needs to become more effective in the prevention of medical healthcare utilization among those cared for at home. Older people who are granted long-term care at home may otherwise imply increased utilization of medical healthcare.[10]

Age is the biggest risk factor for dependency on care. According to a prognosis of the EU-Project FELICIE (Future Elderly Living Conditions in Europe), under the "Healthy Life Gain Scenario" dependency on care until 2030 will increase by 20% for women and by 80% for men after the age of 75. Indeed, the share of older people in all fatal injuries in the EU has been steadily rising by approximately 1% every two years (from 40% in 1997 to 49% in 2006). Annually, 120 000 people in the EU aged 60 die annually due to consequences of injuries. The injury fatality rates rise sharply after the age of 70. Falls are the main causes of fatal injuries among older people.[11] Figure 6 shows fatal injuries amongst older people by causes of death.

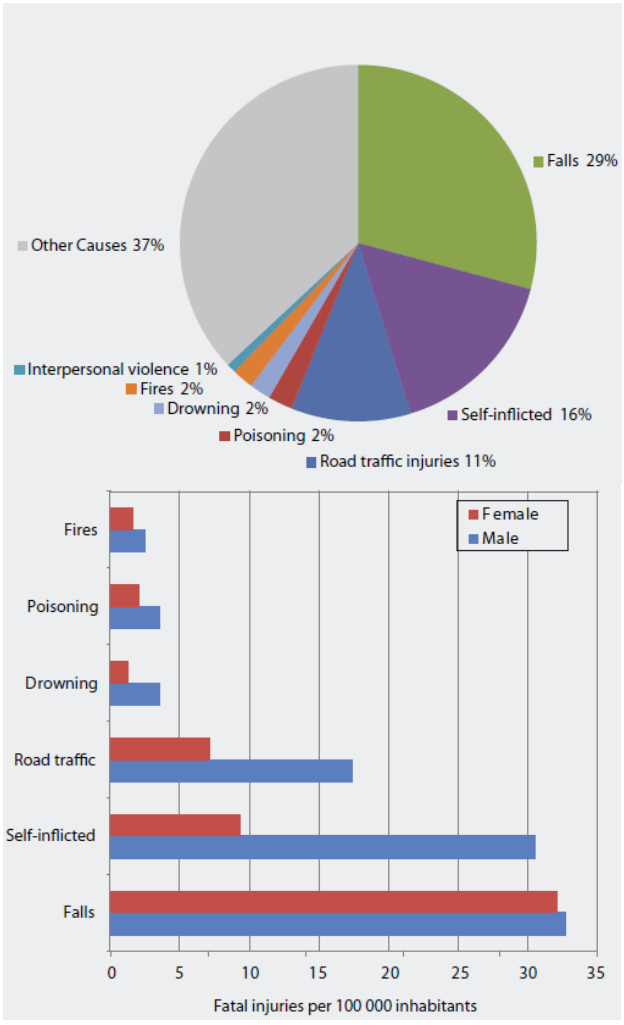


Figure 2 Fatal injuries amongst older people (60+) by causes of death and sex (adopted from Bauer and Steiner, 2009, p. 12 [12])

When it concerns non-fatal injuries of older people, the home (about 60%) and streets (20%) are the most relevant places for occurrence. Gender differences exist in particular in home injuries, which primarily reflect the different exposure to work at home between men and women.[13] Figure 3 shows places of occurrence of injuries amongst older people and activities leading to home injuries.

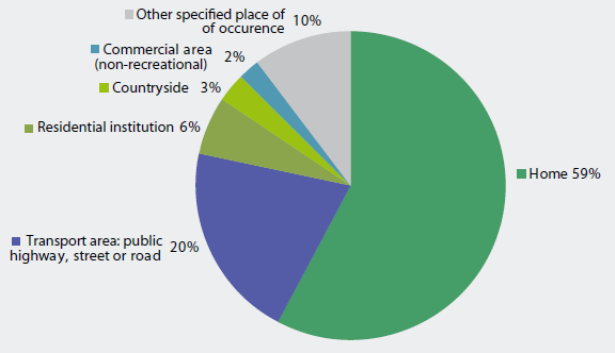


Figure 3 Places of occurrence of injuries amongst older people (60+) and activities leading to home injuries (adopted from Bauer and Steiner, 2009, p. 13 [14])

As a conclusion, there is an evident and urgent need to increase the knowledge of services and systems that increase the home safety of elderly people. Indeed, both academic as well as practical knowledge is needed. The purpose of this empirical study is to increase the knowledge of designing services and systems for safety of elderly people at home. The focus is on ICT-systems which can support elderly people living independently and safely at home. This report results from an on-going action research. Thus, any results and conclusions suggested here are tentative.

2 TECHNOLOGIES TO ENHANCE THE SAFETY OF ELDERLY IN THEIR HOMES

Several technologies can be used to improve safety and lower risk of injury of elderly at home. According Daniel, Cason, and Ferrell [15], such technologies fall into five categories:

- General adaptive technologies. These are the most ‘‘low tech’’ of all applications. They include such things as lever door handles, amplifiers on door bells and telephones, grab rails and handrails in appropriate locations, ramps, stair lifts, external lighting with passive infra-red, lowered light switches, raised electrical outlets, level thresholds, wider doors and corridors, and electric window and door openers [16]. These technologies help older people to stay independent in their homes longer, delaying expensive moves to congregate living arrangements while maintaining quality of life [17].
- Passive environmental sensors. These are devices that monitor the safety features of the home as well as individuals in the home. They usually have low obtrusiveness as they are entirely passive. Examples of passive environmental sensors include devices to monitor gas leaks, carbon dioxide, and other potential hazards. Motion sensors are another example of passive adaptive technologies. These technologies increase the safety of senior adults and help to maintain their independence.
- Assistive technologies. They help elderly in meeting their daily needs and may be useful for elderly who are physically disabled, but still cognitively intact. They include, for example, voice activation technologies of various devices, smart mail box notifies, and alert systems.
- Wander management systems. This system tracks patients with cognitive impairments (CI) such as Alzheimer’s, Down’s syndrome, and autism. It happens through a watchsized bracelet that emits a silent, low-level radio frequency. The system is activated only when a caregiver reports the CI person is missing. Participating local

authorities can then ‘‘tune in’’ the specific frequency for the device issued to that individual.

- Appliance technology. Using radio frequency identification, the technology – smart wave – has the capability of recognizing the type of food product selected, and based on the selection, an instructional video is displayed indicating the steps for preparation. The smart wave has the ability to program itself for the appropriate cooking time. When the food is cooked it notifies the person via audio and video announcement that the food is completed, and also cautions the user when handling the food.

Drawing on Eriksson and Timpka’s [18] study, successful safety technologies for elderly should be unobtrusive, easy to use, and economically viable. They (ibid.) argue that the greatest challenge for the designers of such systems is not technical, but rather to integrate health functions in the correct products (i.e., household items) and to make the health functions attractive to consumers. Consumers may not behave in a way that is considered rational from a technical perspective. There are other factors in addition to functionality and cost, such as design, fashion, lifestyle, status, and general trends in society.

3 SMART HOMES AND AMBIENT INTELLIGENCE (AmI)

Smart environments can assist with valuable functions such as remote health monitoring and intervention. The need for the development of such technologies increases due to the aging of the population, the cost of formal health care, and the importance that individuals place on remaining independent in their own homes.[19] The term “Smart Home” is used for a residence equipped with technology that allows monitoring of its inhabitants and/or encourages independence and the maintenance of good health [20]. To function independently at home, individuals need to be able to complete Activities of Daily Living (ADLs) such as eating, dressing, cooking, drinking, and taking medicine [21]. Figure 4 shows an example of a smart home test bed used by researchers of smart environments.[22]

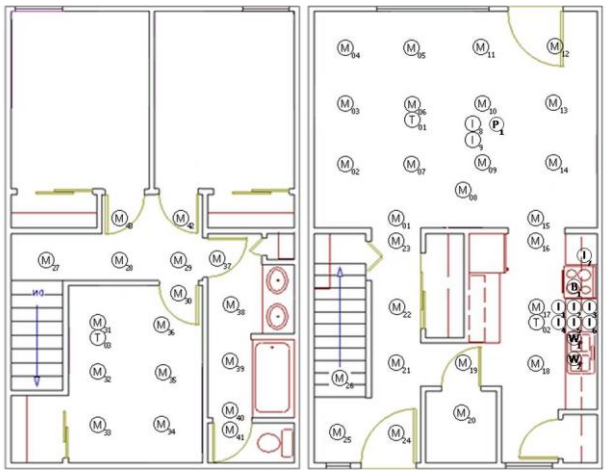


Figure 4 The smart apartment testbed. Sensors in the apartment monitor motion (M), temperature (T), water (W), burner (B), telephone (P), and item (I) use.(Adopted from Crandall and Cook, 2009, p. 2, [23])

Based on Chan, Campo, Estève and Fourniols, several user groups can benefit from Smart Home technologies [24]:

- People living alone who are unable to seek help in emergencies (unconsciousness, falls, strokes, myocardial infarction, etc.).
- Elderly or disabled people who suffer from cognitive (Alzheimer disease, dementia, etc.) and/or physical (visual, hearing, mobility, speech, etc.) impairment.
- People who need help in daily life to perform personal care activities (eating, toileting, getting dressed, bathing, etc.) and instrumental activities (cooking healthy meals, dealing with medication, and doing laundry)[25]
- Informal (family, friends, neighbor people) or formal (care provider) caregivers for the elderly or the handicapped.
- People living in rural and remote communities or in urban communities with inadequate health service provision.
- People living in rural and remote communities or in urban communities with inadequate health service provision [26]
- People who suffer from chronic disease, and who need continuous monitoring (diabetes, cancer, cardiovascular disease, asthma, COPD, etc.)[27]
- People involved in telehealth care undertaking health care at a distance or telemedicine, with physicians practising 'virtual visits' [28]

"Ambient Intelligence" (AmI) is a term closely related to Smart Homes. Smart Homes are, in fact, an application of AmI. The term Ambient Intelligence was used by the European Union to refer to a potential future in which we will be surrounded by intelligent objects and in which the environment will recognize the presence of persons and will respond to it in an undetectable manner [29]. Ambient Intelligence is an emerging discipline that brings intelligence to our everyday environments and makes those environments sensitive to us. AmI research builds upon advances in sensors and sensor networks, pervasive computing, and artificial intelligence. Ambient intelligence systems are sensitive, responsive, and adaptive. This highlights the dependence on context-aware computing.[30] It refers to the presence of a digital environment that is sensitive, adaptive, and responsive to the presence of people [31]. In an AmI environment, people are surrounded with networks of embedded intelligent devices that can sense their state, anticipate, and perhaps adapt to their needs [32]. Such a digital environment proactively, but sensibly, assists people in their daily lives [33]. AmI is a vision of a future daily life and contains the assumption that intelligent technology should disappear into our environment to bring humans an easy and entertaining life [34].

According to Cook, Augusto and Jakkula, sensing, reasoning, and acting are basic functions of AmI [35].

- Sensing. Effective use of sensors is vital for AmI. Sensors are the key that link available computational power with physical applications. Sensors are used to position measurement, for detection of chemicals and humidity sensing, and to determine readings for light, radiation, temperature, sound, strain, pressure,

position, velocity, and direction, and physiological sensing to support health monitoring [36]. Sensors are typically small, they may be wireless, and often use power from batteries. Environmental monitoring, situational awareness, and structural safety monitoring are examples of sensor application areas.

- Reasoning. Sensing and acting provide links between intelligent algorithms and the real world where they operate. In order to make these algorithms responsive, adaptive, and beneficial to users, a number of types of reasoning must take place. Reasoning includes user modelling, activity prediction and recognition, decision making, and spatial-temporal reasoning.
- Acting. AmI systems tie reasoning to the real world through sensing and acting. Intelligent and assistive devices provide a mechanism by which AmI systems can executive actions and affect the system user, for example an elderly person. Another mechanism for acting is through robots. Robots are able to provide an increasing range of assistive tasks to support AmI. They can monitor the vital signs of their masters, provide conversational stimulation, exhibit more human-like emotions and expressions than in the past and even influence human decision [37].

According to Chan, Campo, Estève and Fourniols [38], as difference people have varying needs, the provision of assistance must be tailored to each individual [39]. Smart Homes contribute to caring the elderly, people with chronic illness, and disabled people living alone at home. This new approach to health assessment can improve the quality and variety of information transmitted to the clinician. Measures of physiological signs and behavioral patterns can be translated into accurate predictors of health risk. This can happen already at an early stage, and can be combined with alarm-triggering systems as a technical platform to initiate appropriate action. Telecare and smart homes can provide the infrastructure for coordinating multidisciplinary care outside the hospital. This can include, for example, scheduling visits with health staff and community health workers, automating collection of clinical findings and test results. Chan, Campo, Estève and Fourniols introduced a model of key organization in Smart Home (Figure 4).

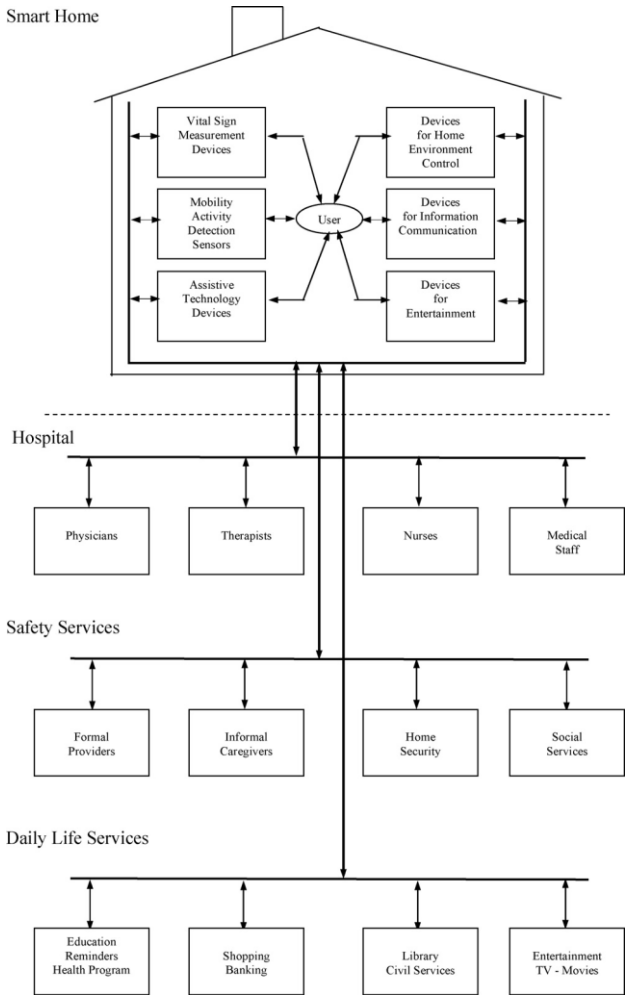


Figure 4 Key organization in Smart Home (adopted from Chan, Campo, Estève and Fourniols., p. 95 [1])

4 AN ONGOING EMPIRICAL STUDY

Next, the present ongoing empirical study is described. The study aims at designing services and systems for safety of elderly people at home is briefly described. This relates to the research project which is a part of ITEA2 (Information Technology for European Advancement) strategic cluster project "GUARANTEE – A Guardian Angel for the Extended Home Environment".

[1]M. Chan, E. Campo, D. Estève and J-Y. Fourniols, J-Y., "Smart homes – Current Features and future perspectives," Maturitas, 64, p. 95, 2009.

Technologies that can support elderly people to live independently at home rather than being institutionalized by delivering customised support in a non-intrusive and respectful way are envisaged as one of the main solutions for a significant reduction of health-care costs. Home safety is one of the important aspects for the elderly. With increase in life expectancy come many other issues like health problems, difficulty in moving around or possibility of getting injured. Accidents are one of the major causes of hospital admission, morbidity and mortality among the elderly. It is therefore important to increase the elders' awareness of safety in everyday life and to introduce technological means to improve it.

Several applications of all generations of telecare (from simple user activated alarms to advanced remote home management and remote therapy services) have been developed, piloted, and tested on an experimental basis in the context of various European projects' R&D programmes, but few of them are currently being delivered on a commercial basis. This is due to several reasons, the most important of which are (a) the lack of commonly agreed standards and technology platforms to support these new services, which gives rise to problems concerning the interconnectivity, interoperability and further extension of these systems; and (b)lack of business model and the delay in the initiation of a social dialogue on the costs and benefits of technological solutions, given that this dialogue did not accompany the development of these technologies in a timely manner.

The research focuses on

- Social impacts, issues and concerns of elderly and disabled about safety in their home environment.
- Ethical issues including privacy, informed consent and others arising from the deployment and use of home safety products and services
- Designing a conceptual model for safety solution services for elderly at home

Indeed, in this study, we aim to contribute to the social and ethical analysis of home safety products and services for elderly and disabled.

An end-user study will be done that answers the research questions and gives powerful insights that will propel the design process. The end-user research's main goal is to examine and identify issues and concerns of elderly and disabled people about safety in their home environment. The end-user research will be done in cooperation with partners that are providing the end-users and test environment. Different meetings and sessions will be planned to identify, gather and analyze the required information.

It is important to get an overview of the context in which the design needs to be implemented and the users for whom it is meant. This understanding is mandatory for Laurea to be able to act as an effective facilitator taking the needs and perspectives of the different players into consideration. Laurea aims to facilitate the interaction between technology

providers, service providers and users (Figure 5). “Laurea” refers our research group at Laurea University of Applied Sciences in Figure 5.

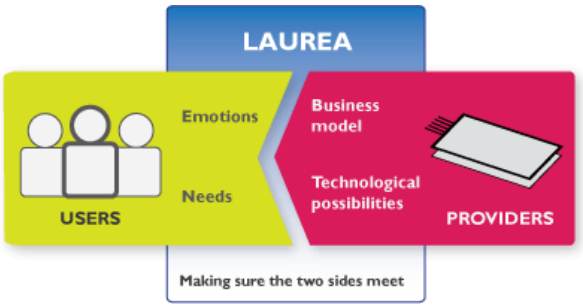


Figure 5 Focus of the research

Understanding how a safety service concept can give people a peace of mind and contribute in increasing the quality of lives while simultaneous preventing accidents, is a crucial part of the research. A good safety concept including ways of support could boost elderly and disable people’s confidence, makes them feel more secure and would enable them to handle day-to-day activities with more ease.

Ethical issues including privacy, informed consent and others arising from the deployment and use of home safety products and services will be researched while social impacts will be identified.

Also, the objective is to design a conceptual service model which delivers a set of safety solutions to the end-user internally or through external collaboration (Figure 6). The eventual design will include a safety solution which involves end-users, technology providers and service providers. The roles of the different actors will be visualized.

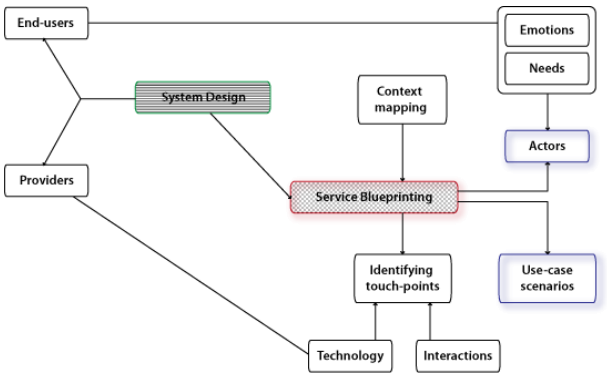


Figure 6 Conceptual service model

The service design approach results in an overall picture of the service experience. This way the design is not only limited to the system, but also for example external service providers are integrated in the design phase. While interaction design is computer based and about designing the interaction between users and products, service design involves the design of the overall service experience including computer based products as part of the touch points.

The blueprint will include identifying touch-points in the safety solution. The technology and the nature of interactions between users and applications will determine the function of the touch-points.

5 CONCLUSIONS

This article explained an ongoing study aiming at designing services and systems for safety of elderly people at home. Both academic as well as practical knowledge is needed. First this article explained why the research and development in this area is relevant. Then, it discussed various technologies to enhance the safety of elderly in their homes. After that, it discussed smart homes and ambient intelligence. Next, it explained the ongoing empirical study. The research focuses on examining social impacts, issues and concerns of elderly and disabled about safety in their home environment. Also, ethical issues including privacy, informed consent and others arising from the deployment and use of home safety products and services are investigated. Moreover, a conceptual model for safety solution services for elderly at home will be designed.

References

[1] Centers for Disease Control and Prevention, 2003. Public Health and Aging: Trends in Aging. United States and Worldwide. MMWR Weekly, Feb 14, 52(06), 101-106. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5206a2.htm, viewed 9 Feb 2010.

[2] U.S. Census Bureau. International database. Table 094. Midyear population, by age and sex. Available at http://www.census.gov/population/www/projections/natdet-D1A.html, viewed 9 Feb 2010.

[3] Australian Bureau of Statistics. Disability, aging and carers, Australia, 1996. Catalogue No 4430, Canberra.

[4] Centers for Disease Control and Prevention, 2003. Public Health and Aging: Trends in Aging. United States and Worldwide. MMWR Weekly, Feb 14, 52(06), 101-106. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5206a2.htm, viewed 9 Feb 2010.

[5] K. Kinsella K and V. Velkoff, U.S. Census Bureau. An Aging World: 2001. Washington, DC: U.S. Government Printing Office, 2001; series P95/01-1.

[6] U.S. Census Bureau, International database. Table 094. Midyear population, by age and sex. http://www.census.gov/population/www/projections/natdet-D1A.html, viewed 9 Feb 2010.

[7] Centers for Disease Control and Prevention, Public Health and Aging: Trends in Aging. United States and Worldwide. MMWR Weekly, Feb 14, 52(06), pp. 101-106, 2003. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5206a2.htm, viewed 9 Feb 2010.)

[8] A. Meijer and C. van Campen, and A. Kerkstra, "A comparative study of the financing, provision and quality of care in nursing homes. The approach of four European countries: Belgium, Denmark, Germany and the Netherlands," J. Adv. Nurs. 32, pp. 554–561, 2000.

[9] A. Bergmark, M.G. Parker and M. Thorslund, "Priorities in care and services for elderly people: a path without guidelines?," J. Med. Ethics 26, pp. 312–318, 2000.

[10] A. Condelius, I.R. Hallberg and U.L. Jakobsson, "Medical healthcare utilization as related to long-term care at home or in special accommodation," Archives of Gerontology and Geriatrics, 2009, article in press, appeared in electronic form, viewed 9 Feb 2010.

[11] R. Bauer and K. Steiner, Injuries in the European Union, Vienna, 2009. https://webgate.ec.europa.eu/idb/documents/2009-IDB-Report_screen.pdf, viewed 6 Jan 2010.

[12] Adopted from R. Bauer and M. Steiner, Injuries in the European Union, Vienna, 2009, p. 12. https://webgate.ec.europa.eu/idb/documents/2009-IDB-Report_screen.pdf, viewed 6 Jan 2010

[13] R. Bauer and M. Steiner, Injuries in the European Union, Vienna, 2009. https://webgate.ec.europa.eu/idb/documents/2009-IDB-Report_screen.pdf, viewed 6 Jan 2010.

[14] R. Bauer and M. Steiner, Injuries in the European Union, Vienna, 2009, p. 13. https://webgate.ec.europa.eu/idb/documents/2009-IDB-Report_screen.pdf, viewed 6 Jan 2010

[15] K.M. Daniel, C.L. Cason S. and Ferrell, S., "Emerging Technologies to Enhance the Safety of Older People in Their Homes," Geriatric Nursing, 30 (6), pp. 384-389, 2009.

[16] R.H. Friedman, J.E. Stollerman, D.M. Mahoney and L. Rozenblyum,"The virtual visit: using telecommunications technology to take care of patients," J Am Med Inform Assoc, 4, pp. 413-25, 1997.

[17] J.M. Argimon, E. Limon and C. Cabezas,"Health-related quality-of-life of care-givers as a predictor of nursing-home placement of patients with dementia," Alzheimer Dis Assoc Disord, 19, pp. 41-4, 2005.

[18] H. Eriksson and T. Timpka, "The potential of smart homes for injury prevention among the elderly, Injury Control and Safety Promotion, 9 (2), pp. 127-131, 2002.

[19] P. Rashidi, D. Cook, L. Holder, and M. SchmitterEdgecombe, M., "Discovering activities to recognize and track in a smart environment," IEEE Transactions on Knowledge and Data Engineering, forthcoming. http://www.eecs.wsu.edu/~cook/pubs/tkde10.pdf, viewed 9 Feb 2010

[20]M. Chan, E. Campo, D. Estève and J-Y. Fourniols, J-Y., "Smart homes – Current Features and future perspectives," Maturitas, 64, pp. 90-97, 2009.

[21] B. Reisberg, S. Finkel, J. Overall, N. Schmidt-Gollas, S. Kanowski, H. Lehfeld, F. Hulla, S.G. Sclan, H.-U. Wilms, K. Heininger, I. Hindmarch, M. Stemmler, L. Poon, A. Kluger, C. Cooler, M. Bergener, L. Hugonot-Diener, P. H. Robert and H. Erzigkeit, "The Alzheimer's disease activities of daily living international scale (adl-is)," International Psychogeriatrics, vol. 13(2), pp. 163–181, 2001.

[22] A. Crandall and D. Cook, "Coping with multiple residents in a smart environment," Journal of Ambient Intelligence and Smart Environments, 1, pp. 1-12, 2009.
[23] A. Crandall and D. Cook, "Coping with multiple residents in a smart environment," Journal of Ambient Intelligence and Smart Environments, 1, p. 2, 2009.
[24]M. Chan, E. Campo, D. Estève and J-Y. Fourniols, J-Y., "Smart homes – Current Features and future perspectives," Maturitas, 64, pp. 93, 2009.
[25] E.D. Mynatt, A.S. Malenhorst, A.D. Fisk and W.A. Rogers. "Aware technologies for aging in place: understanding user needs and attitudes," Pervasive Computing, 3(2), pp. 36–41, 2004.
[26] S.M. Finkeslstein, S.M. Speedie, G. Demiris, M. Veen, J.M. Lundgren and S. Potthoff S, "Telehomecare: quality, perception, satisfaction," Telemedicine Journal and e-Health, 10(2), pp. 122–8, 2004.
[27] T.L. Finch, M. Mort, F.S. Mair and C.R. May, "Future patients? Telehealth care, roles and responsibilities," Health and Social Care in the Community, 16(1), pp. 86–95, 2008.
[28] G. Demiris, " Electronic home health care: concepts and challenges," International Journal of Electronic Healthcare, 1(1), pp. 4–16, 2004.
[29] IST Advisory Group, Scenarios for ambient intelligence in 2010, European Commission, Community Research, 2001. ftp://ftp.cordis.europa.eu/pub/ist/docs/istagscenarios2010.pdf, viewed 6 Feb 2010
[30] D.J. Cook, J.C. Augusto, and V.R. Jakkula, forthcoming, "Ambient intelligence: Technologies, applications, and opportunities," Journal of Pervasive and Mobile Computing, forthcoming. http://www.eecs.wsu.edu/~cook/pubs/pmc10.pdf, viewed 9 Feb 2010
[31] Phillips Research, Ambient intelligence: Changing lives for the better, 2007. www.research.phillips.com/.
[32] A. Vasilakos and W. Pedrycz, "Ambient Intelligence, Wireless Networking, and Ubiquitous Computing," Artech House Publishers, 2006.
[33] J.C. Augusto and P. McCullah, "Ambient intelligence: Concepts and applications," International Journal on Computer Science and Information Systems, 4(1), pp. 1-28, 2007.
[34] C.K.M. Crutzen, "Invisibility and the meaning of ambient intelligence," International Review of Information Ethics, 6, pp. 1-11, 2006.
[35] D.J. Cook, J.C. Augusto and V.R. Jakkula, "Ambient intelligence: Technologies, applications, and opportunities," Journal of Pervasive and Mobile Computing, forthcoming. http://www.eecs.wsu.edu/~cook/pubs/pmc10.pdf, viewed 9 Feb 2010
[36] B. Naja, K. Aminian and A. Paraschiv-Ionescu, F. Loew, C. Bula and P. Robert, P., "Ambulatory system for human motion analysis using a kinematic sensor: Monitoring of daily physical activity in the elderly," IEEE Transactions on Biomedical Engineering, 50(6), pp. 711-723, 2003.
[37] C. Brezeal and B. Scassellati, "A context-dependent attention system for a social robot," Proceedings of the International Joint Conference on Artificial Intelligence, 1146-1151, 1999.

[38] B.G. Celler, N.H. Lovell and J. Basilakis, " Using Information technology to improve the management of chronic disease," Medical Journal of Australia, 179(5), 242–6, 2003.

[39] M. Chan, E. Campo, D. Estève and J-Y. Fourniols, J-Y., "Smart homes – Current Features and future perspectives," Maturitas, 64, pp. 90-97, 2009.